



## Can sharing education between home and school benefit the child with autism?

LAWRENCE, Clare

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**Can sharing education between home and school benefit the child with autism?**

Clare Lawrence

A thesis submitted in partial fulfilment of the requirements of

Sheffield Hallam University

for the degree of Doctor of Philosophy

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## ABSTRACT

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This qualitative research exploration uses interpretative phenomenological analysis of case studies to investigate the diversity and congruity of the lived experiences of families sharing education between home and school for children with autism. Using semi-structured interview and follow-up questionnaire it examines the perspectives of five mothers, and includes further input from wider family members and professionals.

Findings are presented as idiographic cases, examined through the 'lens' of nine research propositions to have emerged through the researcher's complete-member orientation, and further presented in cross-case synthesis under three super-ordinate themes to have emerged: that shared education is a response to need; that it is a response to both perceived positives and perceived negatives in the school experience; and that it is used by parents as a 'bridge'. Findings are considered in the light of similar studies (Kidd and Kaczmarek, 2010; Hurlbutt, 2011) into the experience of parents home-educating their children with autism, together with a study (McDonald and Lopes, 2014) into parents sharing the education of their autistic children between home and the Schools of Isolated and Distance Education in Western Australia.

Findings suggest that there is considerable agreement on the challenges faced by the child with autism in school, on the parents' motivations for intervening and on the parents' endorsement of the literature-supported report on the importance of parental involvement in a child's education. Participants agree that sharing education between home and school can lead to benefit for their child, although the heterogeneity of the autistic population and the diversity of individual participant circumstances lead to a lack of congruity as to the form that this benefit may take.

## **ACKNOWLEDGEMENTS**

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## Index of acronyms and initialisms

**ABA** Applied Behaviour Analysis

**ADHD** Attention Deficit Hyperactivity Disorder

**APA** American Psychological Association

**ASC** Autism Spectrum Condition

**ASD** Autism Spectrum Disorder (or Autism Spectrum Difference)

**BBC** British Broadcasting Corporation

**CfBT** Centre for British Teachers (now the Education Development Trust)

**CME** Complete Member Ethnography

**DCSF** Department for Children, Schools and Families

**DfE** Department for Education

**DfES** Department for Education and Science

**DIR** Developmental Individual-difference Relationship-based (‘Floortime’)

**DSM** Diagnostic and Statistical Manual of Mental Disorders

**EHC** Education and Health Care

**EHE** Elective Home Education

**HMSO** Her Majesty’s Stationary Office

**ICD** International Classification of Diseases

**IPA** Interpretative Phenomenological Analysis

**IPSEA** Independent Parents Special Education Advice

**ITT** Initial Teacher training

**LEA** Local Education authority

**LSA** Learning Support Assistant

**MLD** Moderate learning difficulty

**MRI** Magnetic Resonance Imaging

**NAS** National Autistic Society

**NASUWT** National Association of Schoolmasters and Women Teachers

**NHES-PFI** National Household Education Survey- Parent and Family Involvement

**OED** Oxford English Dictionary

**OfSTED** The Office for Standards in Education

**PACT** Pre-school Autism Communication Trial

**PDA** Pathological Demand Avoidance

**PECS** Picture Exchange Communication System

**PSHE** Personal Social and Health Education

**SEN** Special Educational needs

**SEND** Special Educational Needs or Disability

**SIDE** Schools of Isolated and Distance education (formerly Western Australian Correspondence School)

**SLD** Severe Learning Difficulty

**SpLD** Specific Learning Difference

**SPELL** Structure Positive approaches Empathy, Low arousal environment and strong Links with other agencies including families

**TA** Teaching Assistant

**TDA** Development Agency

**TEACCH** Treatment and Education of Autistic and Communication related handicapped Children

**UNCRC** United Nations Convention on the Rights of the Child

**WHO** World Health Organisation

## Codes and pseudonyms for participants in this study

### Primary participants:

CY and Coby

DN and Ben

GE and Adpar

TE and Elliot

SS and Edward/Eloise

### Secondary participants:

LL (Coby's tutor)

EE (Edward and Eloise's key-worker)

GB (Coby's grandfather)

FY (Coby's father)

NB. For reasons explained in this thesis, this study was conducted under the researcher's professional name of Clare Lawrence.



# 1 INTRODUCTION

---

## 1.1 STATEMENT OF THE PROBLEM

'Everything is so busy at school and everyone else, all the kids and all the teachers, seem to have a purpose and I [as a pupil with autism] have never quite fathomed out what that purpose is. I know we are there to learn, but there seems to be so much more going on than that. It is like beginning a game without knowing any of the rules or passwords.'

[Jackson, 2002 p. 114]

According to the Department for Education (DfE) report into Special Educational Needs (SEN), 2.8% of pupils in England have a Statement of Special Education Needs (Statement) or an Education and Health Care (EHC) plan, and of these, 25.9% has Autism Spectrum Disorder (autism) as their primary type of need (DfE, 2016). This makes autism the most common primary type of need for children with a statement or EHC plan. Additionally, 4.7% of children receiving SEN support without a Statement or EHC plan are identified as having autism as their primary type of need. Autism is a persistent deficit in social communication and social interaction where the person displays restricted, repetitive patterns of behaviour, interests, or activities (DSM-5, 2013).

In the UK children are required to be in full-time education from the ages of 5 – 16, and in full-time education, full-time training or apprenticeship or part-time education plus voluntary work until the age of eighteen (DfE, 2013). The majority of children with autism will receive their education at mainstream school (DfE, 2016), although the percentages of children attending special schools is increasing, from 38.2% in Maintained special schools in 2010 to 42.9% in 2016, and 4.2% in Non-maintained special schools in 2010 to 5.7% in 2016 (DfE, 2016). In total, there are 654 Maintained

and Non-maintained special schools in England which have autism as their formally approved provision, the most common approved provision type (DfE, 2016).

In addition to the options of mainstream or special schools as alternatives for children with autism, some parents consider Elective Home-Education (EHE). Statistics on numbers of home-educated children in the UK are incomplete as not all parents who home-educate register as doing so (Badman, 2009). However, responses to Freedom of Information requests from 190 local authorities show over 36,000 children as home-educated in 2016, a 65% increase in recorded cases in the last six years (BBC news, December, 2015).

There are no statistics available on numbers of children who experience 'shared education', who attend school on a part-time basis in the UK, with the remainder of their education taking place at home (Arora, 2006; Badman, 2009). The practice of sharing education between home and school is relatively prevalent in the USA, where it may even outnumber full-time home-education as a provision (Schafer & Khan, 2016). In the UK, also, cases of shared education do exist, and specifically there are examples where the child has autism (Reid, 2011). Shared education may occur at the request of either the parents or of the school. The National Autistic Society (NAS) is clear that 'informal exclusion' (the school requesting that the parents take their child home for some or all of the school day or week) is unlawful (Reid, 2011). Despite this, 32% of respondents in the NAS 2011 'Great Expectations' survey had been asked to collect their autistic child early or take their child home over lunchtime, with 19% of these parents being asked to do so on more than four occasions (ibid.). An alternative to this unlawful shared education through informal exclusion is the legal option for parents to choose to share their child's education, in negotiation with and with the acceptance of

the school. As noted by the Government UK website 'You can teach your child at home, either full or part-time' ([www.gov.uk/home-education](http://www.gov.uk/home-education) accessed 12/11/16).

This research study is undertaken by a parent who undertook the shared education of her own autistic child between home and school from 2005, when he was in Year 2 until 2017 when he left school at the end of Year 13. Her rationale for doing so has been documented (Lawrence, 2012), and included concern for his mental health and his happiness in full-time school, yet a wish for him to continue to access the education system rather than to be fully home-educated. As he grew in maturity and was more able to articulate it, this was also because he identified that shared education was an effective provision for him. Concern about the health and happiness of their children is cited as the main motivation for withdrawing their children with SEN from school in a number of studies into families home-educating children with SEN, and autism specifically (Parsons & Lewis, 2010; Arora, 2006; Kidd and Kaczmarek, 2010; Hurlbutt, 2011). Other studies (e.g. Desforges, 2003; Fan & Chen, 2001; Harris & Goodall, 2007; Henderson & Mapp, 2002) emphasise the importance of parental involvement in all children's education.

## **1.2 ORIGINAL CONTRIBUTION TO KNOWLEDGE**

There is a paucity of research into the experience of families who share the education of their child between home and school. This study considers the research which does exist, specifically that of Schafer and Khan (2016) into data gathered through the National Household Education Survey in the United States and that of McDonald and Lopes (2014) into the experience of parents sharing the education of their autistic child between home and the Schools of Isolated and Distance Education (SIDE) in Australia. It is the first to investigate the sharing of education between home



and school in the UK as an education provision for children with autism. Its focus is on how parents sharing the education of their child with autism between home and school in the UK make sense of that shared education and of the benefit that they perceive that it brings to their child. As such, it makes an original contribution to knowledge in the field of autism education.

### **1.3 PURPOSE OF THE STUDY**

The purpose of this study is to investigate the experiences of five parents sharing the education of their autistic child or children between home and school, and of the benefits, if any, which they believe that this shared education brings. A 'shared education' in this context is defined as one that takes place for some time in the regular school week at school, and some time in the regular school week directed by the parent or parents (either at home or elsewhere). It also includes provision where some element of the home-education element is delivered by a tutor or mentor at the direction of the parent, but not where the home-education element is as a specific intervention delivered by an external agency where the provision is, in effect, closer to Dual Placement (as discussed later - see 2.2.5). It does not differentiate between legal shared education (that which is undertaken at the instigation of the parents and in discussion with, and with the cooperation of, the school) and unlawful shared education (that which is imposed by the school) since, for the parents, the result remains an education which is shared. It is hoped that the articulation of the lived experience of the parents in this study, however, will reflect the different qualitative experience which this distinction makes.

### **1.4 OVERVIEW OF RESEARCH DESIGN**

The research approach for the study is that of interpretative phenomenological analysis. The primary participants in this study are five mothers sharing the education

of their autistic child or children. Volunteer sampling (O'Leary, 2004) was used from within the self-selected target group of those who share education, drawn from members of the Facebook group Flexi-schooling Families. Volunteer sampling is self-selecting rather than representative, since those who volunteer are likely to be different from those who do not volunteer. The focus of the study is on the parents' self-created understanding of benefits to their child of an education shared between home and school. Participants are self-selecting, both through their membership of the 'Flexi-schooling' web group, and through their interest in taking part in the study. The study does not purport them to be a representative sample, but rather is interested in their understanding of, and articulation of, the benefits which they believe that shared education brings to their autistic children. The data for the study was collected through semi-structured interview (Galletta, 2013), conducted either face-to-face or via email exchange, according to the preference of the participant. Face-to-face interviews took place either in the participants' homes or at a venue of their choosing. Interviews were recorded and transcribed, then coded for emergent themes. Validation was made through direct member checking (Lincoln & Guba, 1985), and widened to include a questionnaire completed by the participants and able to be passed additionally, at their discretion, to 'other interested parties'. These parties included the father of one of the children, the grandfather of two of the children and two professionals working with the children, one as a home tutor and one as a support assistant.

## **1.5 STRUCTURE OF THESIS**

The thesis examines the literature available on the subject of parental involvement in children's education, both as it occurs when the child has autism and when he or she does not, and when the child is educated at school and when he or she is educated at home. There is an absence of available literature on when that education is

shared, although a model of home-education of autistic children undertaken with support from the Schools of Isolated and Distance Education in Australia (SIDE) is considered (McDonald, 2010; McDonald & Lopes, 2014), and recent research into home-educating families who additionally access school support in the USA (Schafer & Khan, 2016) is discussed. The thesis also defines the current understanding of autism and considers both the challenges which autism presents to education and the various approaches to education for children with autism which are available. It examines research on the motivation of parents of children with SEN, and autism specifically, who withdraw their child from school and electively home-educate (Parsons & Lewis, 2010; Arora, 2006; Kidd & Kaczmarek, 2010; Hurlbutt, 2011; Kendall & Taylor, 2016).

In chapter three the rationale for the study's approach, and the philosophical and epistemological position of interpretative phenomenological analysis which supports it, are considered, together with the theoretical propositions which underpin its design. In chapter four the methods employed to collect data for the study are described, and the ethical issues raised by the study are discussed.

Chapter five describes the approaches used to analyse the data gathered, and the ways that this data, and the analysis of it, was verified and validated.

The findings are presented in chapter six, and discussed in chapter seven. Discussion is through the lens of the theoretical propositions to emerge from both the literature review and from auto-ethnographic reflection, and through comparison with parents' experiences as described in similar research projects (Kidd & Kaczmarek, 2010, and Hurlbutt, 2011) which explore the lived experience of parents of autistic children who fully educate their children at home, and that of two families home-educating their

child with autism with the support of SIDE in Western Australia (McDonald & Lopes, 2014).

Finally, conclusions are drawn, suggestions for future research are discussed and the limitations of the study are examined.

# **Map of research design** 'Can sharing education between home and school benefit the child with autism?'

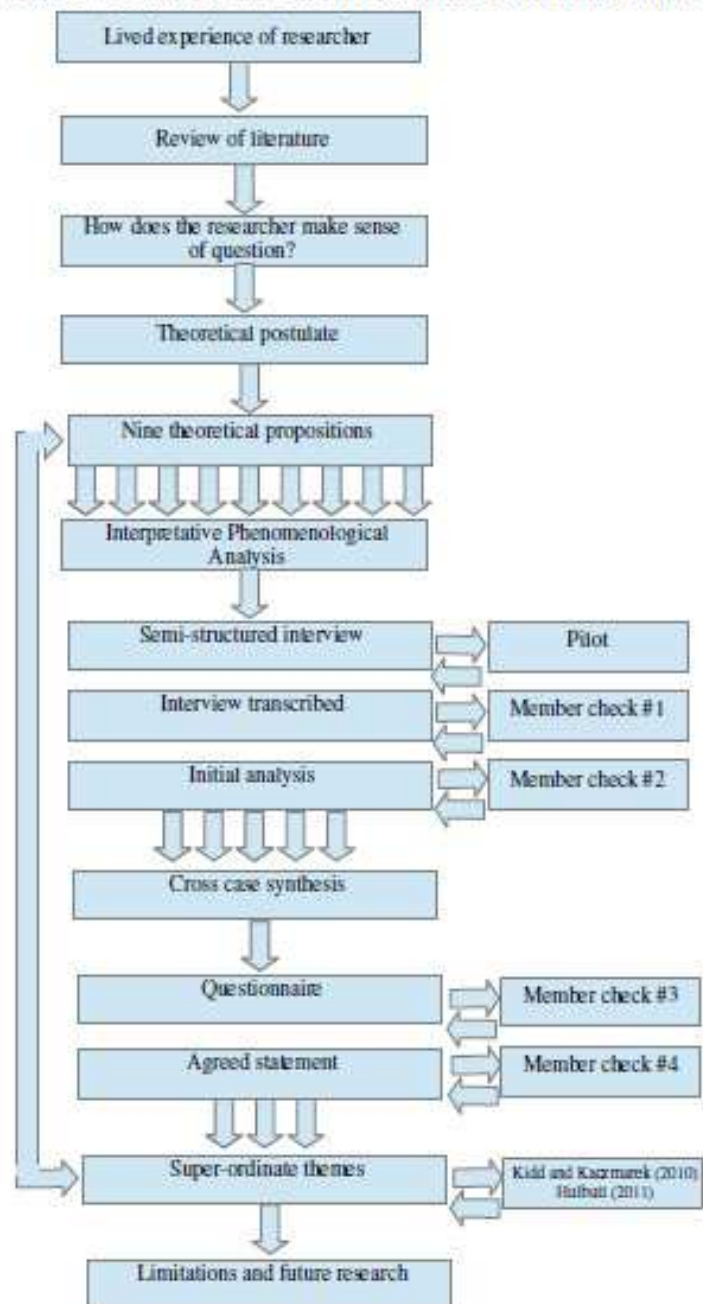


Figure 1: Map of research design

## **2 CHAPTER TWO: LITERATURE REVIEW**

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This chapter explores the historical and personal context which informs this study, and places the concept of 'shared education' within the context of current understanding of autism. It explores how autism presents a challenge to the current education system and how (and why) parents are a vital piece in the autism education jigsaw. It discusses the literature on parental involvement in education, both generally and in an autism context, and investigates whether autism may provide a barrier to the parental involvement recommended by that research, risking further disadvantage to autistic children's education. It investigates parents' involvement as full-time elective home-educators, and explores the extent to which the term 'elective' can always be viewed as accurate when the child has Special Educational Needs or Disability (SEND). It reports studies into the experiences of those who home-educate their children with autism, and investigates indications that parents who do so might choose for their child to continue some involvement with school were this to be made available. Finally, it describes the concept of 'shared education', reports on the sparse literature available on the subject and identifies the gap in the literature on shared education as an educational option for children with autism.

### **2.1 UNDERSTANDING OF AUTISM**

#### **2.1.1 Historical context of the study**

In 2006, Baroness Warnock reopened the debate on the best placing of children with Special Educational Needs (SEN; also termed Special Educational Needs or Disability, SEND) in our education system (Warnock, 2006). Her article in the Philosophy of Education Society of Great Britain pamphlet revisited her earlier (1978) report on the inclusion of children with SEN into mainstream schools. In this she had

argued for the right of children with SEN (then termed 'handicapped') to receive their education alongside their non-handicapped peers. Subsequently she expressed concerns about the way this philosophy had been implemented in the intervening thirty or so years. Inclusion, she argued, was at times leading to suffering:

The children who really suffer from the present system are those whose disabilities are not obvious or visible, particularly those at the moderate end of the autistic spectrum, who may also suffer from moderate learning difficulties (although many Asperger's children are highly, if idiosyncratically, intelligent), not to mention communication and/or behavioural difficulties (Warnock, in Cigman, 2006, pxi).

The history of the education of children with SEN in this country is, according to Low 'bedevilled by dogma' (2007, p. 3). Where earlier the philosophy had been that children with SEN should be segregated into institutions, with Warnock's 1978 report this changed to one where children with SEN were included alongside their peers (Frederickson, Jones & Lang, 2010). The advantages to the inclusion model were understood to be that it taught disabled children to grow up as members of a non-disabled world and that it fostered an attitude that disability, in whatever form, was a natural component of human variability (Low, 2007). Although Low acknowledges that inclusion can do much to help 'normalise' disability, he maintains that inherent in the right to inclusion should be the right for the child not to avail him or herself of that model if preferred. Lindsay (2007) identifies that the main driver for inclusive education is philosophical and is concerned with children's rights, principally the concept that segregation of disabled children from their typically-developing peers compromises those rights. He also identifies that the relative effectiveness of inclusive education is a separate issue and that although there is interaction between them, rights and effectiveness need to be considered separately.

Wing (2007) adds to the debate by focussing on the specific needs of children with autism. She argues that the differences experienced by children with autism can make inclusion in mainstream wholly inappropriate for some of these children. She suggests that 'even the most able children with autistic disorders may find mainstream school intolerable' (Wing, 2007, p.32). Others (for example, Norwich, 2005; Norwich and Lewis, 2005) argue that the needs of children with autism may not be met in mainstream school, that exclusions are higher from mainstream than from special schools for pupils with autism (Barnard et al., 2000) and that pupils with autism in mainstream schools may be less able to regulate their emotions and behaviour (Ashburner, Ziviani & Rodger, 2010). A comparative study of the impact of mainstream and special school placement on the behaviour of children with autism (Reed, Osborne & Waddington, 2016) found that children in specialist autism provision made greater improvement in the areas of socialisation and conduct over the course of a school year than did those placed in mainstream provision.

### **2.1.2 Autism diagnostic criteria**

A definition of autism is not simple and is confused by the fact that the criteria for autism diagnosis are complex and at times contradictory (Wing, 1990). Additionally, there are also a number of positions ontologically regarding what autism 'is': whether it is a disability or a neurological difference which is part of the normal spectrum of human experience. It can be understood using a medical model of disability, defined as a 'physical or mental impairment that has a 'substantial' and 'long-term' negative effect on [the] ability to do normal daily activities' (UK Equality Act, 2010), or a social one, which argues that 'that we were not disabled by our impairments but by the disabling barriers we face in society' (Oliver, 2013, p. 1024).



The current diagnostic criteria for Autism Spectrum Disorder given in DSM-5 (2013), the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders used as standard classification of mental disorders by mental health professionals are, in summary:

- A. Persistent deficits in social communication and social interaction and
- B. Restricted, repetitive patterns of behaviour, interests, or activities.

The social communication and social interaction aspect is further subdivided into categories of deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviours used for social interaction and deficits in developing, maintaining, and understanding relationships. The restricted behaviour aspect is further subdivided into categories of stereotyped or repetitive motor movements, insistence on sameness, restricted, fixated interests and hyper- or hypo-reactivity to sensory input (DSM-5, 2013).

This inclusion of autism in this manual of 'mental disorders' is noteworthy. According to the Mental Health Act (HMSO, 2007, Cited in Hall & Ali, 2009) a mental disorder is defined as, 'Any disorder or disability of the mind'. DSM-5, however, includes a distinct subcategory for 'Neuro-developmental disorders' (including autism) separate from psychotic disorders and various other mental disorders. There is a distinction being made between disorders of the mind, as explored in the field of psychiatry, and those of the brain, as explored in neurology (White, Rickards & Zeman, 2012).

The other major means of autism classification in use is the World Health Organisation's 'ICD-10: Classification of Mental and Behavioural Disorders' (1993).

ICD stands for the 'International Classification of Diseases'. A disease, according to the Oxford English Dictionary (1986) is 'an unhealthy condition of the body or of the mind'. The ICD-10 criteria for autism include:

- a) Qualitative impairment in reciprocal social interaction
- b) Qualitative impairment in communication
- c) Restrictive repetitive and stereotyped patterns of behaviour, interests and activities

These criteria are similar to, but clearly not precisely the same as, those defined in DSM-5. DSM-5 additionally includes the new condition of Social (Pragmatic) Communication Disorder, and removes the previous inclusion of Asperger syndrome, which still exists under ICD-10.

Asperger syndrome in ICD-10 is 'an autistic spectrum disorder' which is 'similar to autism' with which it 'shares many of its symptoms', but which has facets that differentiate it from autism (World Health Organisation, 1993). Under DSM-5, Asperger syndrome has ceased to exist and has been subsumed under the more general category of Autism Spectrum Disorder.

### **2.1.3 Terminology**

Pupils who are currently of school age (as are the children in this study) may have received a diagnosis of Asperger syndrome, as opposed to Autism Spectrum Disorder, using either ICD-10 or the version of DSM, DSM-IV, in use at the time of diagnosis, and they or their parents may prefer to continue to use that term. Other widely used terms include the initials ASD (for Autism Spectrum Disorder) or ASDs (for Autism Spectrum Disorders) or the initials ASC (for Autism Spectrum Condition). The concept of 'diagnosis' is not accepted by those who see autism as a neurological

difference rather than a disorder and the language of 'identification' is preferred (Kapp, Gillespie-Lynch, Sherman & Hutman, 2013). Confusingly, this 'neuro-diversity' movement (for example, Baker, 2006; Kapp et al., 2013) may also use the initials ASD, standing for Autism Spectrum Difference. The term 'autistic' was used by both Asperger and Kanner to describe what they identified, independently of each other, in the 1940s. It is also the term most favoured by autistic adults (Kenny et al., 2016). The adjective 'autistic' meta-morphed into a noun in the 1950s, taking the suffix '-ism', which, according to the Oxford English Dictionary (1996), denotes, amongst other things, a 'basis for prejudice or discrimination ... [or] a pathological condition'.

Nevertheless autism/autistic are the term used in this study as the least value-laden of those available. Within this study 'autistic person' and 'person with autism' are used interchangeably. The American Psychological Association (APA) Publication Manual (2009) guidelines for reducing bias recommend the avoidance of 'language that objectifies a person by his or her condition (e.g. autistic)', recommending instead the use of person-first language ('person with autism') as a 'preferred expression [to] avoid the implication that the person as a whole is disabled' (APA, 2009). However, many people within the autistic community prefer the use of identity-first language ('autistic person') as suggesting that the autism is intrinsic to the person and not a (negative) appendage to that person (Sinclair, 2013; Kenny et al., 2016). In this study, 'child with autism' and 'autistic child' are both used in order to indicate the writer's neutral stance on this issue, and are used specifically to describe a neurological difference, the aetiology and pathogenesis of which are currently unknown but which results in the presentations both positive and negative experienced by the person.

#### **2.1.4 Concept of autism**

When autism was initially identified by Kanner (1943) and Asperger (1944) the prevalent approach to understanding it was psycho-analytical, with a concentration on emotion and attachment, and particularly on parenting as the 'cause' of autism (Kanner, 1943; Bettelheim, 1959). In the 1960s, Rimland, himself the parent of a child with autism, suggested autism could be biological, not psychological (Rimland, 1964).

Approaches to autism consequently became more behaviourist, led by practitioners such as Lovaas who believed in the concept of 'normalisation', and that non-autistic behaviour should be trained into the child (Lovaas, 1977; 1987). More recently, the role of sensory differences in autism has become better understood, largely through an increase in research which recognises the lived experiences of people with autism (Grandin, 2000; Jackson, 2002; Williams, 1998; Bogdashina 2001, 2016; Little et al., 2015; Ausderau et al, 2014; Iarocci & McDonald, 2006; Leekam, Nieto, Libby, Wing, & Gould, 2007). Many experiences of autism such as anxiety and depression have been suggested by the autism community to be the bi-product of the autistic person having to negotiate a non-autistic world rather than being intrinsic to autism (Fenton & Krahn, 2009). Other research suggests that differences in the amygdala in the autistic brain may explain increases in fear and anxiety response in people with autism (Amaral, Bauman & Mills, 2003).

The advent of new technology (for example, the MRI scan) has led to increased awareness of the neurological differences in the autistic brain, for example in surface brain differences in the cerebral cortex (Hazlett, Gu et al., 2017). However, awareness of differences in brain structure have not always increased understanding of what these differences may mean for the person with autism (Libero & Kana, 2013) as although imaging may clarify the diagnosis of autism as neuro-developmental, the interpretation

of brain differences to understand autism experience remains challenging. For example, the differences observed in the amygdala and attributed by Amaral, Bauman and Schumann, (2003) to increased anxiety and fear response in autism are the same differences in the amygdala as those attributed by Sebat et al., (2003) to impairment in social function.

The emphasis on differences in the autistic brain at the genetic and neural level (for example, Tang et al., 2014; Huguet, Benabou, & Bourgeron, 2016; Samson et al., 2001) can support those who see autism as a disorder and who advocate for research to reduce or ultimately eliminate autism. This 'medical model' of disability is supported by organisations (for example, Autism Speaks) who support bioscientific research into the causes of autism. The medical model can be contrasted with the 'social model' of disability (for example, Oliver, 1990; Oliver and Barnes, 2012), that 'we were not disabled by our impairments but by the disabling barriers we faced in society' (Oliver, 2013, p. 1024).

The polarity of these two positions is not, however, total. Some who recognise the emergence of medical evidence for autism also argue that the cognitive and biological differences of autism do not in themselves indicate disorder (Lai, Lombardo, & Baron-Cohen, 2014). In his editorial piece in the *Journal of Child Psychology and Psychiatry*, Simon Baron-Cohen argues that:

the term 'disorder' implies the natural order has gone awry and that the individual's underlying cognition and neurobiology is dysfunctional in some way ... But when we examine the cognition and biology of autism, arguably what we see is not evidence of dysfunction but rather evidence of difference.

(Baron-Cohen, 2017, p. 277)

The idea that difference need not indicate deficit is central to the Neurodiversity movement, first described by Blume (1998), with his suggestion that the autistic brain is simply one manifestation of human diversity. This view is compatible with the 'civil rights plea for minorities to be accepted with respect and dignity, and not be pathologised' (Baron-Cohen, 2017, p. 278), and echoes the language of biodiversity, with its inherent valuing of diversity as richness. This more respectful language does not reject the concept that the differences in the autistic brain are real and measurable, nor does it suggest that many of the manifestations of these difference may be very challenging for the autistic person. It does, however, indicate an acceptance that autism does not imply inherent impairment, and it is the philosophical position adopted in this study.

#### **2.1.5 The concept of 'Benefit' as explored in this study**

Within the confused landscape around discussion of autism it can be difficult to navigate to a position where the concept of 'benefit' in autism can be defined for use in this study. Potential empirical focusses which have been used to assess autism interventions include – amongst others – those around social, communication, behavioural, cognitive, academic, and joint attention behaviours (Odom & Wong, 2015). However, this study does not use a positivist approach of 'benefit' which can be measured in an empirical way. Instead it is interested in the personal construction of that benefit as made by the participants (parents of autistic children sharing that child's education between home and school). It uses parental report to elucidate their understanding of the stresses on their child which they believe that school attendance produces and the ways, they believe, that reduced school time and increased home time through shared education may reduce those stresses. Further, it elucidates their understanding of the advantages which both at-home and at-school time may bring to

their children. As such, the parents are enabled to construct their concept of 'benefit', as experienced by them and by their child. Although self-report questionnaires are regarded as the primary method for assessing quality of life, specifically that which is health-related (Vogels et al., 1998), proxy by parent is a useful alternative where language skills and/or cognitive ability make self-report problematic (Theuneissen et al., 1998). 'Benefit' for the child with autism, in the context of this study, will be considered within the parameters of a reduction of elements which might impact negatively on the child, and/or the increase of elements which might impact positively on the child, as understood and articulated by the parent. It will additionally be explored within a framework of any potential longer term benefits to children beyond the participants in this study.

## **2.2 AUTISM AND EDUCATION**

### **2.2.1 Current practices in the education of children with autism**

There is a lack of agreement as to best practice in the education of children with autism (Parsons et al., 2011; Lindsay, Proulx, Thomson & Scott, 2013; Lindsay, Proulx, Scott & Thomson, 2014). Evidence suggests that young people with autism are struggling in schools, particularly in mainstream schools, experiencing issues with isolation and loneliness (Chamberlain, Kasari, Rotheram-Fuller, 2007), peer rejection (Frederickson, Jones & Lang, 2010; Humphrey & Symes, 2010) negative self-perception (Hebron & Humphrey, 2013) and bullying (Cappadocia, Weiss, & Pepler, 2012; Humphrey & Symes, 2010).

Research by the National Autistic Society of Northern Ireland (2012) reports that more than one in four (27%) of the young people with autism surveyed said they did not feel happy at school, and one in five (20%) said they did not feel safe at school.

Additionally, of the parents and carers surveyed in the NAS 2015 survey of England, 42% of respondents said that their perception was that school had “got worse” over the last three years, with only 13% suggesting it had “got better” and 28% that it had “stayed the same”, and 75% of respondents stated that it had not been easy to get the educational support their child needs (NAS, 2015, p. 5).

As already indicated (2.1.1), there has been a movement in the last decade which argues against the efficacy of inclusion of all children with special or additional needs into mainstream schools. There has been a reported rise in discontent with the education system in parents of autistic children (Lynch & Irvine, 2009) and an increase in demand for autism-specific education (NAS, 2015). In 2015 the National Autistic Society reviewed educational provision for pupils with autism in England via an online survey completed by over 1,400 parents/carers and 231 young people under 25. Results include that one in four children is not in the type of school preferred by their parents and, as had been suggested in Lynch and Irvine's 2009 research, two thirds of parents who were not happy with their child's school would prefer 'autism specific' provision, either at a unit attached to a mainstream school (32%) or at an autism specific special school (31%).

However, there is no one agreed approach to the education which is supplied in an ‘autism specific’ provision. For example, Iovannone, Dunlap, Huber and Kincaid (2003) describe six elements that they claim have empirical support and should be included in 'any sound, comprehensive instructional program for students with ASD' (p150). These are:

- (a) individualised supports and services for students and families
- (b) systematic instruction



- (c) comprehensible/structured learning environments
- (d) specialised curriculum content
- (e) functional approach to problem behaviour
- (f) family involvement.

However, there is no universal agreement that these elements, or any other, should form the approach for a special school or unit. The National Autistic Society schools follow the 'SPELL' framework (providing Structure, Positive approaches and expectations, Empathy, a Low arousal environment and strong Links with other agencies, including family) (Povey, 2009), and other approaches include TEACCH (the Treatment and Education of Autistic and Communication related handicapped Children), (Mesibov & Howley, 2003), or ABA (Applied Behavioural Analysis), (for example, Lovaas, 1977).

In 2011, Parsons et al. undertook an international review of empirical research and expert evidence (dated 2002–2008) to identify best practice in educational provision for children with autism. They reviewed the findings of 92 peer-reviewed research papers and drew on expert evidence from policy documents and government strategies in the UK and Ireland. Their findings report insufficiently strong evidence regarding the effectiveness of any one type of intervention approach compared with another and recommended that a 'range of educational provision should be maintained in order to cater appropriately for a wide diversity of needs' (Parsons et al., 2011, abstract, pi).

### **2.2.2 Challenges posed by school for pupils with autism**

Children with autism experience differences in communication, social interaction and flexibility of thinking and behaviour (DSM – 5, 2013). Their alternative way of thinking, learning and experiencing the world and themselves pose complex

challenges for schools (Jordan & Powell, 1995). Many require explicit teaching of skills and understanding, elements of the curriculum which are outside that usually provided in mainstream schools (Whitaker, 2007). Schools contain a huge range of potentially serious stressors for children with autism, including demands for social interaction, sensory overload and limited levels of structure (Whitaker, 2007; Attwood, 2007; Kelly, Garnett, Attwood, & Peterson, 2008).

Challenges facing the autistic child at school include:

- Differences in the way the child processes information from the senses
- Differences in the way the child both initiates and understands social communication
- Differences in language usage and processing
- Bullying, loneliness and/or social isolation
- Anxiety and depression
- Lack of academic progress as measured against intelligence predictors

Sensory processing differences may provide a challenge for the autistic child at school as he or she may experience an unusual response to any of the five widely recognised senses (hearing, sight, touch, smell and taste) or to others such as vestibular (balance), proprioception (body awareness) and interoception (pain, hunger, thirst – internal body awareness) (DSM-5, 2013). The child may be both hyper- and hypo-sensitive to sensory stimuli, often fluctuating between the two extremes (Jones, Quigley & Huws, 2003; Iarocci & McDonald, 2006; Leekam et al., 2007). Understanding of this element of autism is not new; sensory symptoms featured in the original descriptions of autism (Asperger, 1944; Kanner, 1943), and were further explored by Wing (1979), and Hermelin and O'Connor (1970). However, awareness of the part that sensory

differences play in the difficulties experience by pupils with autism in school has increased during this century, not least through eloquent accounts written by people with autism (for example, Grandin, 2000; Jackson, 2002; Williams, 1998) and discussed in a range of research (for example, Bogdashina 2001, 2016; Jones et al., 2003; Little et al., 2015; Ausderau et al., 2014).

School may pose a challenge in that autism involves a difference in social communication and social interaction (DSM-5, 2013). The child with autism will have altered communication for social purposes and may not communicate in a manner appropriate for the social context (Van Bergeijk, Klin & Volkmar, 2008). He or she may not change communicative style to match context or the needs of the listener, may struggle to follow the rules for conversation and may not understand the use of verbal and non-verbal signals to regulate interaction (Attwood, 2007). He or she may struggle with inference, idioms, humour or metaphors and with understanding multiple meanings that depend on the context for interpretation (DSM-5, 2013; Attwood, 2007). The issue of language understanding and usage differences in autism has been somewhat confused since 2013 by the creation of the condition Social (Pragmatic) Language Disorder in DSM-5 (DSM-5, 2013), which appears to segregate many of the language related elements of autism into this separate condition (Swineford, Baird, Thurm, Swedo, & Wetherby, 2014). However, a diagnosis of Social (Pragmatic) Communication Disorder can only be given after a diagnosis of autism has been ruled out (American Psychiatric Association, 2013) so that all of the language differences described are likely also to be present as part of the wider differences of autism (Swineford et al., 2014). The presence of language differences within autism is well documented (for example, Attwood, 2007; Mandy & Skuse, 2008). As reported in the Bercow Report (DCSF, 2008), the ability to communicate is an essential life skill which underpins a child's

social, emotional and educational development. The anecdotal experience for people with autism of trying to 'interpret' the language of school is articulated in the literature (for example, Jackson, 2002; Sainsbury, 2000).

Barriers to social communication and social interaction can lead to a lack of social acceptance, and to the experience of bullying (Attwood, 2007; Cappadocia, Weiss & Pepler, 2012; Hebron & Humphrey, 2013; Kelly et al., 2008; Chamberlain, Kasari & Rotheram-fuller, 2007; Rotheram-fuller, Kasari, Chamberlain, & Locke, 2010). The need for support to develop peer relationships (for example 'Circle of Friends', O'Connor, 2016) is the greatest reported concern of parents of children with autism (NAS, 2015), with 62% of respondents in the NAS survey identifying it as the support which they would most like for their child but do not get. The vulnerability of autistic children in school to social exclusion and other forms of bullying is well recognised, both in personal report (for example, Sainsbury, 2000; Jackson, 2002) and in research. Batten et al. (2006) report that over 40% of children with autism have been bullied at school. In 2016 Maïano, Normand, Salvas, Moullecand and Aimé undertook a systematic review and meta-analysis of the literature, concluding that 'school-aged youth with ASD were found to be at greater risk of school victimisation in general, as well as verbal bullying, than their typically developing peers' (p. 601). As well as name calling, ostracising and excluding, physical taunts and ridicule, the child with ASD may be vulnerable to being 'set up' to do things that get him into trouble, his social naivety making him a target, as do his different behaviours and his social isolation (Atwood, 2007).

Anxiety and depression are prevalent in people with autism (Van Bergeijk, 2008; Ghaziuddin, 2005; Matson & Williams, 2014). The pressures and pace of school

are widely reported by people with autism (for example, Jackson, 2002) to be contributory to feelings of anxiety. Research suggests that nearly half of children diagnosed with autism may also meet diagnostic criteria for clinical anxiety (Sukhodolsky et al., 2008). This pressure at school may be relieved for the young person with autism by short breaks, something which many parents indicate as something which they would like their child to receive in the school day (NAS, 2011).

Depressions in autism is reported as being above the average for the general population (Chandrasekhar & Sikich, 2015; Matson & Williams, 2014; Rieski, Matson et al., 2015; Ghaziuddin, 2005; Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998) and research suggests that suicidal thoughts and attempts are significantly higher in autism than the norm (Mayes, Gorman, Hillwig-Garcia & Syed, 2013).

Pupils with autism may underachieve academically at school according to intelligence quotients predictors (Ashburner, Ziviani & Roger, 2008; Estes, Rivera, Bryan, Cali & Dawson, 2011; Keen, Webster & Ridley, 2016). Explanations for this underachievement include reduced ability to learn through imitation and observation (Plavnick & Hume, 2013; Fleury et al., 2014) and the inability to disengage from repetitive and stereotypical behaviours (Zandt, Prior & Kyrios, 2007). There is also a lack of specialist provision available in mainstream schools, with parents highlighting occupational therapy, support from mental health specialists and speech and language therapy as supports which they would like their child to access but which they are not receiving (NAS, 2011; 2015). Parents are requesting, additionally, support for their children in the areas of daily living skills and leisure or play opportunities (NAS, 2015).

### **2.2.3 The placing of children with autism in education**

The argument on the optimum placing of children with autism for their education centres around the options of mainstream school ('inclusion') versus special

school ('segregation'). Cigman (2006) argues that this is a false alternative. Whilst acknowledging the important premise that 'we are *all* in favour of inclusion' (Cigman, 2006, p. xvii), she suggests that there are important arguments about the philosophical nature and extent of that inclusion, and when segregation can or should be alternatively framed as specialisation (Norwich & Lewis, 2005).

Running parallel to this argument between the advantages and disadvantages of mainstream versus specialist provision for children with SEN is another less visible one between the options of school education and home-education (Arora, 2006; Parsons & Lewis, 2010, Kidd & Kaczmarek, 2010; Hulbutt, 2011). Central to this argument is the role that society places on all parents in the education of their children, the added input to that role undertaken by some parents of children with SEN and the extent to which it is government or parents who are responsible for children's education (Badman, 2009).

#### **2.2.4 Dual Placement**

There is provision in legislation in England for a child with autism to attend both mainstream and special school through a system of 'dual placement'. This allows the child to be registered at both a mainstream and a special school and to share his or her education between the two. The DfES document Inclusive Schooling (2001, para. 58) states that, 'The appropriate use of dual placements – where a child can attend more than one school – can support inclusion.' However, the document goes on to make clear that dual placement is seen primarily as a way to enable a child who would otherwise attend a special school full-time to have some access to mainstream, or to prepare for transition between special and mainstream schools.

The exception to this is where parents withdraw their autistic child from some elements of full-time school education in order for that child to access an autism-

specific programme. These programmes vary, but may include, for example, programmes such as Applied Behavioural Analysis (ABA), Son-rise ('Options'), Sensory Integration Therapy, Auditory Processing Intervention, DIR ('Floortime'), Cognitive Behavioural Therapies and Intensive Interaction Therapy (Research Autism, n.d.). In these cases, the child's school-delivered education is supplemented, or sometimes replaced, by a programme-delivered curriculum, which may take place at the school, at a clinic or at home.

## **2.3 PARENTAL INVOLVEMENT IN EDUCATION**

### **2.3.1 The importance of parents in children's education**

In the 'range of educational provision' (Parsons et al., 2011, abstract, p. i) recommended by Parsons et al., one element appears to have been largely overlooked: parents are a powerful element in the success or otherwise of their children's education. There is a considerable body of research to have emerged over the last thirty years that suggests involving parents in their child's schooling produces benefits. See and Gorard (2015) indicate that many large scale, longitudinal studies show a strong association between parental involvement and children's school outcomes (e.g. El Nokali, 2010; Desforges, 2003; Gfeller, McLaren & Metcalfe, 2008; Hango, 2007). Reported benefits of parental involvement have included, for example, increased academic attainment (Fan & Chen, 2001; Harris & Goodall, 2007; Henderson & Mapp, 2002; Jeynes, 2007; Sui-Chu & Willms, 1996), increased attendance (Epstein & Sheldon, 2002); improved behaviour (Harris & Goodall, 2007) and more developed social skills (Henderson & Mapp, 2002).

The importance of involvement by parents in their children's education is recognised by the UK Government's inspection office 'Ofsted', which suggests that schools should demonstrate determination in their efforts to engage with parents. In

order to be classed as 'Outstanding', a school must demonstrate that it has 'highly successful strategies for engaging with parents' (Ofsted 2015, p. 49). The Department for Children, Schools and Families (DCSF) published research in 2007 entitled 'Engaging Parents in Raising Achievement – Do Parents Know They Matter?' (Harris & Goodall, 2007) which reported consistent evidence of the educational benefits of involving parents.

Lall, Campbell and Gillborn (2004) agree that involvement of parents in children's education is a major contributory factor in overall levels of attainment in school and Peacock (2005), in his foreword to the Scottish Schools (parental involvement) Act, states that parents' active involvement in supporting their child's learning can help the child to do better. Parental involvement in their children's education can, therefore, be seen as 'crucial' (Department for Education (2012, p. 25).

Partnerships between home and school may have a positive influence beyond school performance to broader factors such as helping pupils to forge positive self-identity (Elias et al., 2003). Unfortunately, according to Reed (2009), such partnerships continue to be 'professionally top heavy' (p. 26). She cites the Bercow Report (DCSF, 2008) and the Lamb Inquiry (DCSF, 2009a), saying that findings suggest that parents' contributions, though 'theoretically powerful, remains in practice, marginal, relative to professional view points' (ibid., p. 26).

### **2.3.2 Types of parental involvement**

Research suggestions into best ways to facilitate parental involvement vary and some are relatively 'light touch'. Kraft and Rogers (2015) undertook a field experiment to examine an intervention using the delivery of a weekly, one-sentence message from teacher to parents which indicated ways that the pupil could improve. A similar research



project by Hurwitz, Lauricella, Hanson, Raden and Wartella (2015) delivered parenting tips and activities by text message to parents involved in the HeadStart programme, encouraging them to engage in interactive learning activities with their children. This study involved 256 parents, half of whom received the messages for six weeks. A questionnaire completed at the end of the study indicated that those who received texts took part in more education activities and reported higher levels of satisfaction than those who did not receive the texts. This teacher-parent direction of flow of expertise is mirrored by Tableman (2004), who suggests that 'parent effectiveness is enhanced when the school provides orientation/training; for example, written directions with a send-home instructional packet' (p. 4).

However, other research suggests that the model of the parent being invited to be involved by the school is not effective. Minke and Anderson (2002) examined parent-teacher conferences and found, according to Elias, Bryan, Patrikakou, and Weissberg, (2003), 'a procedure fraught with stress and inequality, as teachers dominated, parents were passive, and children were absent' (p. 145). Further, Minke and Anderson describe something of the quandary of trying to fit meaningful parent-teacher interaction and partnership into already busy lives: 'Exhausted parents showing up to meetings are not a catalyst for a sound partnership. This is compounded when exhausted educators must give up time with their own families to be at these meetings and find them unproductive' (Elias et al., 2003, p. 146).

### **2.3.3 'At-home' discussion as an influence on the child's education**

Desforges undertook a review of the literature on parental involvement in education in 2003, aiming to establish research findings on the relationship between parental involvement and support on pupil achievement in school. He concluded that the most significant positive effect on children's achievement and adjustment was

discussion, undertaken between child and parent, at home, and that this effect was evidenced across all social classes and ethnic groups. He cites two 'technically high quality studies', Sui-Chu & Willms (1996) and Sacker, Schoon & Bartley (2002) particularly that show this at-home interest and support to be a major force in shaping pupils' educational outcomes. He further describes findings by Siraj-Blatchford, Sylva, Muttock, Gilden and Bell (2002) that parents' involvement with their children in at-home learning activities is closely associated with cognitive attainment, and is particularly of benefit when the child's experience is supported by both parent and professional to have continuity. These findings are supported by more recent research by Kaplan-Toren and Seginer (2015) in their two-year longitudinal study which collected data in Israel from 198 students (97 girls) in Grade 7 at the first wave and found parental educational involvement to be influential primarily through home-based involvement.

LaRocque, Kleinman and Darling (2011) caution that there should be no 'one size fits all' approach to parental involvement in children's education. They emphasise the need to see parents and their children as individual and with individual needs:

There is a need to move from [the] idea that parents are the same, with the same needs, and that children should be treated the same. Given that increased level of parental involvement in schools and in the education of their children is positively correlated with increasing educational achievement it is important to devise ways to increase parental involvement' (pp. 115).

#### **2.3.4 Factors influencing parental involvement in their children's education**

Given this body of evidence to suggest the advantages of parental involvement, consideration must be made of the factors which encourage parents to be engaged in their children's education or indeed which deter them from being so. These may

include the extent to which parents see involvement in education as part of their 'job' as a parent (Desforges, 2003). Barriers to parental engagement are investigated more fully by Hoover-Dempsey and Sandler (1995, 1997, 2005) and Green, Walker, Hoover-Dempsey and Sandler (2007). These describe various factors which influence parental involvement in their child's education, including the parents' perceptions of the extent of invitation to involvement made by the school (Green et al., 2007, p. 2). Nor are the factors which may inhibit parental involvement static. For example, Mowen (2015) investigates the influence which the increase in at-school security measures which have occurred over the last decade in American schools may have on parental involvement. He suggests that results indicate that the presence of a security guard and metal detectors in schools may reduce school-based parental involvement, although it does not impact informal parental involvement at home.

### **2.3.5 The effect of SEN on parental involvement**

As early as the Warnock Report (1978) the importance of including parents as partners in their child with SEN's education was being stressed, and the revised special educational needs and disability code of practice (2015) states clearly that 'parents' views are important' (p. 21). However, research suggests that many parents of children with SEN feel that the school does not listen to them enough (Dockerell & Lindsay, 2004) and that parents of children with SEN would welcome greater involvement in their children's education (Peters, 2008). Specifically, parents of children with autism are asking to be more involved. The National Autistic Society (2011) reports that 'top of the list [of parental requests] was professionals listening to parents' concerns and taking them seriously' (p. 13), adding that 'parents of children with autism expect ... to be equal partners in the system and genuinely involved in decisions about their child's education' (p. 3). Parents want schools to accept communication from them more

readily, acknowledging their knowledge of their own child and taking their concerns as parents seriously. They are also concerned that schools communicate with them, so that consistency may be maintained between home and school (NAS, 2011). The voice of the pupil with autism reflects this, as reported in the survey. When asked what would make school better, one pupil with autism quoted in the report replied, 'If they believed my parents more ... I can't show my true feelings at school, only at home, and so they just don't believe I have a problem' (ibid., p. 13).

The very presence of SEN in a pupil should in theory lead to the establishment of a greater partnership between home and school: '[T]he successful education of children with Special Educational Needs is dependent upon the full involvement of their parents' (Warnock, 1978, para 9.1.) Such home-school partnership is intended to empower and involve parents, thereby facilitating partnership (DfES, 2001a), making the involvement of parents of children with SEN an essential element of their successful education (Dockrell & Lindsay, 2004). However, in reality many parents of children with SEN are left feeling marginalised (ibid.).

Two reports are particularly pertinent to this current study and are worth reviewing separately. They are the Badman Review of Elective Home-education in England (2009) and The Lamb Inquiry into Special Educational Needs and Parental Confidence (2009).

#### **2.3.5.1 *The Badman Review (2009)***

The Review of Elective Home-education in England by Graham Badman was commissioned by the government to review the arrangements for home-education in England and was prompted primarily by concerns regarding adequate safeguarding measures for this largely unregulated group. In his review Badman acknowledges many

of the parents who took part in his review to be dedicated and committed and many children in home-education to be thriving. However, he also expresses concerns about the lack of monitoring of home-educated children. The review gives a detailed consideration of the state of home-education in 2009, although it was criticised by some home-education groups for its recommendation of compulsory registration of home-educated children with their local authority. The government accepted the findings of the review and proposed the amendment of the 1996 Education Act to include the required registration, although in July 2009 the DCSF commissioned its own inquiry into the Review which suggested that registration should be voluntary in the first instance. In December 2009, the MP Stuart Jackson filed a petition to the House of Commons demanding that Badman's recommendations be rejected and the proposed changes scheduled for the revised Education Act 2011 were dropped at the General Election of May 2010.

Numbers of home-educated children in England are unknown since there remains no requirement for parents in the UK to register their home-educated children with their Local Authority. This is partly because the responsibility for the provision of a child's education in the UK rests with their parents and it is they who have the duty to ensure that any education provided is 'efficient', 'full-time' and 'suitable', as stated in Section 7 of the Education Act 1996:

'The parent of every child of compulsory school age shall cause him to receive efficient full-time education suitable – (a) to his age, ability and aptitude, and (b) to any special educational needs he may have, either by regular attendance at school or otherwise.'

Badman notes that what constitutes an 'efficient' and 'suitable' education are not defined in law, although he cites case law (*R v Secretary of State for Education and Science*, Mr Justice Woolf, 1985) that gives a broad description of an efficient

education being one that 'achieves that which it sets out to achieve' and a suitable education being one that 'equips a child for life within the community of which he is a member'.

Although primarily focussed on monitoring and safeguarding of home-educated children, Badman makes comment also on the reasons for home-education and gives report of experiences of it. He notes that motivations for parents to home-educate are many and varied, citing Hopwood et al. (2007) that these reasons include, amongst others, bullying and discontent with the quality of education provided in school, particularly the perceived inadequate provision for children with special educational needs.

Badman recognises that children with SEN form a 'special case' within the home-education cohort and dedicates a section of his report to them. He suggests that the evidence offered to his review contains 'very convincing case studies of hardship, anxiety and misunderstanding' (Badman, 2009, para. 7.1) and recognises that parents withdrew their child from school to home-educate 'often in despair that their needs were not being adequately met' (ibid., para. 7.1). He suggests that in the case of parents of children with SEN – and he mentions autism specifically – the situation is often home-education by default rather home-education which can be fairly described as elective.

Amongst these parents home-educating by default with their children with SEN he notes that some (although not all) are keen to maintain contact with the mainstream education sector, welcoming visits by the Local Authority and making use of drop-in centres, resources and materials as available. His recommendations are keen to support contact between parents and the mainstream education sector in these cases.

Recommendation 11 includes that schools should collaborate with these families to extend the option of access to school libraries, sports facilities, school visits and

specialist facilities and key stage assessment. He recommends that schools provide access to specialist music tuition on the same cost basis as for children in school, provide access to work experience and post 14 vocational opportunities and provide signposting to parents to third sector provision as available. Notably, he also recommends that schools 'extend and make available the opportunities of flexi-schooling' (recommendation 11, p.41).

Badman acknowledges parents' place as prime educators for their children, arguing that 'Few would argue ... that parents are the prime educator within or outside of a school system' (para. 1.5). He also makes a 'strong argument' for the commissioning of further research to better understand the efficacy and potency of personalised learning as manifested in home-education (para 3.1).

Furthermore, he is keen to recommend that local authorities analyse the reasons why parents choose elective home-education, and that the concerns that led them to do so be addressed (Recommendation 3). He recommends that the Ofsted review of SEN provision should give due consideration to home-educated children with SEN and make specific reference to the support of those children (Recommendation 17).

Of particular relevance to this study is that Badman is clear about the difference between legal home-education, either that which is genuinely elective (because for example, parents have particular philosophical, pedagogical or religious reasons for wishing it) or that which is 'by default' (when parents home-educate as the only option they can see to keep their children safe), and unlawful or 'forced' home-education at the instigation of the school. He recommends that the DCSF 'takes such action as necessary to prevent schools or local authorities advising parents to consider home-education to prevent permanent exclusion or using such a mechanism to deal with educational or

behavioural issues' (Recommendation 15). This awareness of the continuation of the unlawful practice of 'informal exclusion' echoes findings made by the Lamb Inquiry (2009).

#### **2.3.5.2 *The Lamb Inquiry (2009)***

The inquiry into Special Educational Needs and Parental Confidence undertaken by Brian Lamb was made in response to the House of Commons Education and Skills Committee Report 'Special Educational Needs: Assessment and Funding', and aimed to explore ways in which parental confidence in SEN assessment and provision might be enhanced. The report contains the 'clear message ... [that] ... parents need to be listened to more' (foreword letter to the Secretary of State).

Amongst its range of concerns is the high incidence of school exclusion amongst children with SEN. It cites the DCSF 2009 report that 'about 70% of permanent exclusions are of children with SEN (ibid., p. 35) and that children with SEN are eight times more likely to be excluded than their peers (ibid., p. 3). It reports 'too many instances' where children have been excluded for reasons linked to their SEN because staff have insufficient understanding of the child's communication needs and where 'a communication difficulty was at the heart of the incident that led to an exclusion' (ibid., p. 36). This is despite DCSF (2008) guidance which maps out procedures and adjustments that head teachers should take in any exclusion of a disabled child or a child with SEN.

However, also noted in the report is that the statistics on exclusion of children with SEN do not include so-called 'informal exclusions', occasions where parents are asked by the school to take their child home or not to bring their child into school. Reasons given for this by schools include support staff being absent, staffing being



stretched or to avoid a specific event or trip (ibid., p. 34). The DCSF makes it clear that these exclusions are unlawful. However, parental report confirms that they happen nevertheless, with consequences for the parents on their availability for, or reliability at, work resulting in some parents losing employment or giving up work as a result (ibid., p. 34). The report also notes increased incidence of 'persistent absences' in children with SEN indicating that 47% of primary and 42% of secondary persistent absentees were recorded as having SEN in 2006–07. Although the inquiry identifies that this is more than double the rate observed across the school population, the reasons behind these persistent absences are not explored.

Lamb reports that schools need to engage with parents if children with SEN are to make progress, arguing that training to work with parents should be embedded in the training of all school staff. He welcomes the fact that training for teachers in working with parents of children with SEN was to be included in the Initial Teacher Training (ITT) materials developed by the Teacher Development Agency (TDA), an executive agency for the Department for Education which was relaunched as the Teaching Agency 2012. ITT resources commissioned by the TDA in response to the Lamb Inquiry include units on Working with Parents, noting that children may not express or show difficulties they are experiencing during the school day and that parents can give insight into this from what the child says or does at home. It recommends using the Structured Conversations approach as outlined in Achievement for All (DCSF, 2009), drawing on parents' knowledge to help the school to target its teaching, interventions and activities and to inform school staff about both what the child does well and also the barriers that might impede progress.

The Carter Review (2015) into how well Initial Teacher Training prepares trainees to be teachers recommends creation of a framework of core content for teacher training. Although at the time of this study this is at an early stage, indications are that it will continue to use as its frame of reference the current Teaching Standards which came into force in September 2012 and which define the minimum level of practice expected of trainees and teachers from their initial teacher training (Munday, 2016). These include having 'a secure understanding of how a range of factors can inhibit pupils' ability to learn' (standard 5) and being able to 'communicate effectively with parents with regard to pupils' achievements and well-being' (standard 8).

### **2.3.6 The child as mediator in parental involvement**

Green et al. (2007) assert that 'the most important questions concerning parental involvement ... address why parents choose to become involved' (p. 2). They include amongst the barriers to this involvement, 'parental role construction; parental perceived self-efficacy; invitation, opportunity and demands created by the school *and by the child*' (researcher's italics).

Desforges agrees that one critical component in deciding levels of parental involvement is the role played by the child, suggesting that this role is rarely recognised and has the potential to be enhanced. He identifies that 'the dynamic role of pupils in mediating home-school relations has not been the subject of much research' (Desforges, 2003, 6.13).

### **2.3.7 Autism as a specific barrier to parental involvement**

There appears to be no research into the effect which autism, specifically, has on parental involvement in a child's education nor whether the child's social and communication issues in autism are themselves raising barriers to parental involvement. If a factor of parental involvement is invitation by the child (Green et al., 2007), this is

likely to be reduced by the autistic child's communication differences (Attwood, 2007). If the most effective involvement by parents is home discussion (Sui-Chu & Willms, 1996; Desforges, 2003) this may have significant repercussions for children with autism as talking together at home may be precisely what parents and children with autism find most challenging (Attwood, 2007). This may be especially difficult if the child is already exhausted by dealing with the demands of a full school day and is intent on recharging in solitude, which may be the main emotional recovery mechanism for people with autism (Attwood, 2007). Even if parent and child occupy the same space, discussion of the school day may not come naturally to the child with autism. To even attempt to engage in 'at home conversation' about school, the parent is going to need to have good contextual knowledge of what is likely to have happened at school (Frith, 1994). The parent must, in other words, know what questions to ask. Without these points of reference to use as starting point with the child with autism, 'dropping [a child with autism] into school is like dropping a pebble into a deep, still pond. We may see the ripples, but we are also quite likely to lose the pebble' (Lawrence, 2008, p. 20).

The autistic child's reduced, or altered, social communication (DSM-5, 2013) may itself raise barriers to parental involvement in that child's education. So-called 'dinnertime parental involvement', as discussed by Houtenville and Conway (2008), which includes the informal discussion of activities, events, what has been studied in class, courses or programmes at school, may be challenging for autistic children and their parents. The child with autism is unlikely to report events at school as reduced theory of mind (Baron-Cohen, Leslie & Frith, 1985) may mean that the child is not aware that his experiences are not shared with his parents. Equally, due to reduced central coherence (Frith, 1994), the child may struggle to 'joint the dots' and realise the importance of events or how they interact with one another. Where a parent of a non-

autistic child may be able to access feed-back of information about that child's school day, parents of a child with autism may have little or no information on events, people or emotions (Lawrence, 2008). The child with autism's social isolation may add to this effect. Where the parents of younger neuro-typical children may have other pupils from the school visit the home, giving both information and insight into the world of school and bringing with him or her other parents with whom to 'share notes', the child with autism may not access this social circle (Lawrence, 2008). 'Autistic children are often ... rejected by their class-mates simply because they are different and stand out from the crowd (Asperger [1944] 1991 in Attwood 2007, p. 95).

This combination of the autistic child's social communication difficulties (DSM-5, 2013), the need for solitude and respite from social interaction (Attwood, 2007) and the parents' lack of contextual understanding to know how to enter the child's world (Lawrence, 2008) suggests barriers to the at home interest and support (Sacker et al., 2002) parent-child discussions (Desforges, 2003) and 'dinnertime' parental effort (Houtenville & Smith Conway, 2008) recommended as beneficial in the literature. These may combine to further deny the autistic child the support, through parental input, available to his or her non-autistic peers.

### **2.3.8 Parental involvement as a potential indicator of success in autism intervention**

The value of parents as involved partners in communication with their autistic children is reflected in research. Oono, Honey and McConachie (2013) report finding 'some evidence for the effectiveness of parent-mediated interventions, most particularly in proximal indicators within parent-child interaction (p. 2), with Francis (2005) noting that such mediation 'empowers the parents and makes them feel in control of their child ...[resulting] in a better parenting style and the avoidance of distress and

disappointment' (p. 496). The first results internationally to have shown long-term reduction in negative behaviours associated with autism is an intervention which involves parents (Pickles, Le Couteur & Leadbitter et al., 2016). This follow-up of a parent-mediated intervention, the Preschool Autism Communication Trial (PACT) shows sustained improvement in child autism presentations and social communication with parents, with this improvement being maintained six years after the initial intervention took place. The researchers conclude that the findings from their study suggest the potential long-term value of their parent-mediated interventions. This research suggests that parents can be supported to improved communication with their autistic children, and that this improved communication may be sustained. The research focusses on the effect of early intervention undertaken with children aged 2 - 4. Research on supporting improved communication – specifically through intervention or through increased parent/child time – between older autistic children who have not received this early input and their parents remains to be undertaken.

## **2.4 HOME-EDUCATION**

### **2.4.1 Parents as home-educators**

Research into Elective Home-Education (EHE) has grown considerably in the last decade. Much of it argues that children who are home-educated do at least as well academically as, and sometimes better than, their school educated peers (Thomas, 1998; Rothermel, 2010, 2011, 2012). Boulter (1999) argues against the validity of some research which suggests that home-school education is more academically effective than traditional education, particularly highlighting suggestions that academic gains are not sustained as the child becomes older. However, she agrees that the evidence from her study of 110 students, conducted over a six-year span, confirms findings that suggest that home education is as effective as school-based education in all the major subjects.

This mirrors findings by Webb (1990) that at 'school leaving age' home-educated children's achievements closely parallel those from the school system. Rothermel (2011) cautions that tests results, however, may not give a fair reflection of home-educated children's progress, arguing the inappropriateness of using tests designed for school-educated children to test academic progress in children who are home-educated.

The number of children who are home-educated in the UK is not known (Badman, 2009), although anecdotal evidence suggests that the number is growing (Arora, 2006; Badman, 2009). In 2007 the Department for Education and Science commissioned a feasibility study to test whether it was possible to ascertain the prevalence of EHE in England, but this concluded that this is not possible under current systems of registration.

Motivation for EHE is also diverse and varied. It includes issues that are child related such as negative socialisation, for example bullying, and failure to progress academically, and ones which are school related such as issues of time and resources (Kidd & Kaczmarek, 2010; Reilly, Chapman & O'Donoghue, 2002). Badman (2009) makes the point that the huge range of reasons for home-education mean that it is difficult to identify EHE families as a distinct group with a clear voice or attitude. Rothermel (2011) goes further, suggesting that initial reasons for EHE may not be the same as those for continuing EHE, and that labels in this context are not useful. What is clear in studies is that one factor which influences the decision to home-educate can be that the needs of children with SEN are not being met at school (Arora, 2006; Hopwood, 2007; Kidd & Kaczmarek, 2010). Hurlbutt (2011) identifies more specifically that some parents of children with autism may choose to home-educate because they feel that their child does not respond to traditional methods of instruction,

and that they feel that educating their children with autism at home can lead to improvement in child behaviour and in child psychological well-being. Research suggests that home-educated children generally are both socially and emotionally well-adjusted (Thomas, 1998) and that those with SEN appear to make at least as good academic progress as pupils with SEN in the school system (Parsons & Lewis, 2010).

#### **2.4.2 Extent of parental 'choice' to home-educate children with SEN**

Although in general parents who home-educate their children report high levels of satisfaction with what they are doing (Badman, 2009; Rothermel, 2011), it is not clear how many who home-educate children with SEN would prefer for their children to have some continued access to school should they feel that their needs could be met. Arora (2006) is clear that her data suggests that numbers of parents in this position may be quite high. The Independent Panel for Special Educational Advice (IPSEA) submission to the Badman Review (2009) into Elective Home-education states, 'Some families with children with SEN make a positive choice to educate their children at home. For others, it is the least bad option.' The submission goes on to describe, amongst these least bad options, 'Withdrawal as an act of desperation in the interests of the child's mental or physical well-being (in Badman, p. 25).

Parsons and Lewis (2010) conducted a survey looking at what motivated parents of 27 children with SEN to home-educate. Nearly half of the children in the study had a diagnosis of autism. They report that the majority of parents believed that the school had been failing to accommodate their child's needs. One parent indicated that she had 'been left with no other acceptable option' with another indicating that she had been 'frightened for her sanity and her life' (p. 77). This desperation when school placement goes wrong is echoed by NAS research (Reid, 2011). Quotations from parents in the section 'Consequences of getting it wrong' include, 'He will self-harm and force himself

to be sick upon seeing his uniform' and 'My son ended up suicidal and on Prozac aged ten [due to] his inadequate education' (NAS, 2015, p. 7).

Attitudes generally to home-education are diverse. The National Association of Schoolmasters and Union of Women Teachers (NASUWT) asserts that home-education is anomalous with a well-resourced and fit for purpose education delivered by qualified teachers (in Badman, 2009). This attitude can be summarised by the comment by David Blunkett, the then Secretary of State for Education and Employment, (1999) that 'A child not in lessons is a child not learning'. The contrasting view, that parents are prime educators, regardless of whether that takes place entirely at home through EHE or through some of the child's education being undertaken in school, is seen in the language of the National Children's Plan (DfE, 2007) and quoted by Badman (2009, p. 5): 'Parents not governments bring up children'.

#### **2.4.3 Studies into home-education for children with autism**

Studies which investigate the experiences and motives of parents of children with autism, specifically, who home-educate are rare. Of particular interest to this study are those by Kidd and Kaczmarek (2010) and Hurlbutt (2011). Kidd and Kaczmarek undertook qualitative research within a phenomenological framework similar to that used in this study and explored the lived experiences of ten mothers home-educating children with autism in Australia. Hurlbutt (2011), again used a similar design to explore the experiences of parents who 'homeschool' their children with autism in the mid-west of America. Kidd and Kaczmarek (2010) employed a semi-structured interview to collect data on the experiences of mothers recruited through home-education email support groups and a home-based learning network in Perth. These interviews were audio recorded and transcribed, and analysed using a thematic content analysis techniques. The authors verified conclusions from this process by cross-



checking each other's findings, and further validation of conclusions was sought from a number of the study participants. Hurlbutt recruited the ten parents (nine mothers and one father) for her study through contact with local schools and the State Department, through outside agencies working with home-educate families and through the Homeschooling Association. Data gathering was from face to face interviews, with follow up interviews and email exchanges made to clarify and gain additional information as necessary. The initial interviews were audio recorded and transcribed and data was analysed using an open coding procedure. Reliability was maintained through a peer review of the coding.

Of additional relevance to this research is the study by McDonald and Lopes (2014), into parents who home-educate their children with autism with the support of the School of Isolated and Distance Education (SIDE) in Western Australia. This study builds on findings in previous research (McDonald, 2010) on the experience of two families home-educating their children with autism with the support of SIDE, and focusses on three thematic concerns: 'experiencing a crisis point', 'gaining appropriate support' and 'increasing educational fit'.

Motivation for home-educating children with autism as reported in the literature indicates that it is often as a response by the parents to perceived need. The parents in a study by Kendall and Taylor (2016) into reasons why the parents of eight pupils with SEN (six of whom had autism as their primary diagnosis) chose to home-educate reported that 'there was a lack of understanding about ASD' by school staff (p. 304). Additionally, the parents indicated that they felt that staff were unwilling to listen to their information about ways to support and work with their child. In Parsons and Lewis' survey (2010), where nearly half of the children in the study had a diagnosis of

autism, the majority of motivations to home-educate related to school factors, primarily dissatisfaction, bad experiences or a failure to accommodate the child's needs. One parent indicated, 'We are not choosing home-education as an alternative lifestyle choice, but have been left with no other acceptable option.' Two of the mothers in Kidd and Kaczmarek's study into parents home-educating their children with autism reported that they withdrew their child from school after they began to self-harm '[due to] the stress and anxiety encountered at school' (p. 264). Others gave reasons including bullying, anxiety, distress and, in two cases, on psychologists' recommendation. The most frequently indicated motivation for home-educating given in Parsons and Lewis' study was that the 'child was unhappy/stressed/depressed at school.'

In this context, Parsons and Lewis highlight a problem with the language of the term “elective” home-education, as elective 'implies a positive and informed choice.' They indicate that there is a difficulty 'in the assumption that deciding where and how to educate children, especially those with SEN or disabilities, is a real choice for parents', adding that the role of parents of these children as 'an empowered consumer [is] a myth.' For the parents in their survey the decision to remove their child was reached after periods of substantial unhappiness. They indicate that 'the only way to help their children achieve their potential [has been] to remove them from the state system altogether, often after serious concerns about their children's health and happiness' (p. 84).

## **2.5 SHARED EDUCATION**

### **2.5.1 The concept of 'Shared Education'**

'Shared education' within this study is taken to mean the full-time education of the child as required in law (Education Act, 1996), where some of that education takes place in school and some out of school (Pattinson, 2013), the out of school element

using what is generally termed 'home-education' (although it need not take place within the home), delivered or at least directed by the parent. As such, shared education fulfils the parents' legal obligation to 'cause [their child] to receive efficient full-time education suitable a) to his age, ability and aptitude and b) to any special educational needs he may have either by regular attendance at school or otherwise.' (Education Act, 1996, section 7). 'Otherwise' is generally taken to be home-education, but can be seen in this context to be education that is shared between home and school, and which therefore modifies the concept of 'regular attendance at school'.

It is difficult to gauge from the literature the extent to which parents, specifically those with autistic children, would choose to share education were the option made more widespread. Parsons and Lewis indicate in their home-education with children with SEN survey that 'most of the parents ... suggested they would prefer their children to attend school but only if their needs were adequately met and learning suitably individualised.' They add that, 'There was also some suggestion that provision needed to be sufficiently flexible to accommodate children's changing needs over time, for example, through offering *a mix of school and home-based provision*' [researcher's italics]. Kendall and Taylor (2016) identify that in their study into the reasons why parents of children with SEN choose to home-educate, 'some parents [number not specified] said that they would welcome flexi-schooling with part-time attendance at school' (p. 303), identifying the fact that flexi-schooling is at the discretion of the head teacher as being the barrier to this. One parent (Parent 'A') reported, 'I had planned to try to flexi-schooling but it's so difficult to set up. It's hard to find a head teacher that will do it to be honest' (Kendall & Taylor, 2016, p. 303).

Badman's 2009 review made recommendation to 'extend ... opportunities of Flexi-schooling' (p. 20) and Arora's 2006 review of the literature on home-education with reference to special educational needs similarly provides recommendations that, where the school cannot wholly meet the child's needs and these needs can be fairly seen as being better met at home, the LEA and school should work with the family as part of a 'flexible education plan'. She argues that the school should 'retain some responsibility to provide advice, resources and regular monitoring of these children' as part of a 'well-coordinated arrangement in which children remain on the roll of the school, even if they are partly or wholly educated at home' (p. 63). For some years, therefore, researchers have been recommending shared education as an addition provision available to children whose needs are not being met by full-time school.

Arora (2002) describes shared education in some detail, recommending that:

homes and schools work together to ensure that children's needs are met ... [through] a system of part-time attendance at school, in which the parents and the school take responsibility for delivering different parts of the curriculum in the different locations [p. 26].

### **2.5.2 Flexi-schooling**

Such shared education is often referred to as 'flexi-schooling'. The concept of flexi-schooling was first argued for by Roland Meighan (1988) in his book 'Flexi-schooling – Education for tomorrow, starting yesterday'. In this he describes it as something which emerged from his discussions with educationalist John Holt and uses the term 'to describe [the] notion of a part-time arrangement whereby school and family sharing responsibility in an agreed contract and partnership.' Meighan's philosophy was part of the movement of 'deschooling' which emerged from the writings of Ivan Illich (1973) and involved educational philosophers such as Husén (1979) and Hemming (1980). As such, his concept of flexi-schooling involves more than the sharing of

education 'as is' between home and school and is rather an emergent philosophy of the roles that parents, schools and learners could play in the wider process of education, and a consideration of what that 'education' could or should involve. He advocates for the increased involvement of parents in their children's education as much from a philosophical stance as from a pedagogical one, arguing that the circumstances of parents' exclusion from education are historical (dating from a time when many parents were illiterate and education of children was therefore deemed to be the remit of trained and educated teachers), and that this exclusion both needs and merits reconsideration. He describes a vision of democratic education, the creation of a web of Education Support Hubs, and of his own small alternative school. This is a wider concept of 'flexi-schooling' which goes beyond that which is considered in this (small) study, and consequently this study uses the term 'shared education' in preference. However, as participants were recruited through the Flexi-schooling UK Facebook group and because of the title of the researcher's book on the subject, 'Autism and Flexi-schooling', the term 'flexi-schooling' is used as synonymous with 'shared education' on occasion, especially when it occurs in other literature or is used by participants.

The term 'flexi-schooling' is also increasingly used in Australian studies to indicate a range of more flexible learning experiences and has come to be used in preference to the term 'alternative education' (Shay & Heck, 2015). Flexi-schooling in this context describes models of education outside conventional schooling which aim to enable young people who are at risk or disengaged to remain engaged in education (Te Riele, 2007). The language used to describe young people in danger of disengagement can carry negative connotations (Morgan, Pendergast, Brown, & Heck, 2014), with the term flexi-schooling being preferred as not positing the young people as being the problem (Shay & Heck, 2015).

One model of flexi-schooling in this context, that involving Schools of Isolated and Distance Education (SIDE), is considered in this study. SIDE, originally called the Western Australian Correspondence School, was established in the state of Western Australia in 1918 as a way of addressing the educational needs of isolated children in that state, using a correspondence course profile of delivery in line with that already successfully established in other states of Australia, for example Victoria and New South Wales (McDonald, 2010). Now renamed, it caters for an increasingly diverse body of students and has gone 'beyond the original cohort of geographically isolated students' (ibid., p. 2) to include 'secondary students, 'handicapped' students, those living overseas and Indigenous children' (Eakins, 1964, in McDonald & Lopes, 2014, p. 3). It has an overall aim of being a provision for students who have 'difficulty attending school for whatever reason' (McDonald & Lopes, 2014, p. 3). Discussion of the cases of two families sharing the education of their autistic child between home and the SIDE provision is made in this study.

There is no research yet available about the perspectives of children who share education between home and school. Indeed, even research into the perspective of young people who are fully home-educated is limited, in particular that regarding the perspectives of people with autism. Research undertaken in by Ray on adults in the USA who were previously home educated is positive, indicating that they may 'participate in local community service more frequently ... vote and attend public meetings more frequently than the general population, and go to and succeed at college at an equal or higher rate than the general population' (Ray, 2004, in Ray, 2015, p.2). Additionally, Dolan (2017) suggests that students with autism who were home-educated have lower college attrition rates than those who attended school, stressing 'the importance of support, especially from parents, both during the homeschool years and

during college’ (p. 3). Dolan finds that the college students in her case study, each of whom had been home-educated prior to college admittance, have strong systems of family support already in place as they enter college, and that this support is perceived by the students to contribute to their success at college.

However, whilst there is some research evidence that home-education can meet the academic and support needs of students, some cultures are more wary about it. In 2003, the Federal Constitutional Court in Germany upheld an earlier Federal Institutional Court ruling (Konrad and others vs Germany, 2003) that social integration of children ‘could not be achieved in any other way than attending the closely supervised and controlled system of state and private schools’ (Donnelly, 2016 p. 287). The German state upheld its duty to ‘protect the children from their parents’ decision to home-school because the children could not foresee the long-term consequences of such a decision, since they were too young’ (Donnelly, 2016, p.292). In the UK, additional legislation around home-education is being proposed. A Private Members’ Bill had its first reading on 26th June 2017, with the purpose to amend the 1996 Education Act and to ‘make provision for local authorities to monitor the educational, physical and emotional development of children receiving elective home education’. This amendment is being contested by home-education groups.

Only when adequate research becomes available which enables the voice of the home-educated child, and of the adult reflecting on earlier experience as a home-educated child, will it be possible to make informed assessment of the potential effects, both positive and negative, of home-education. In the absence of any research into the effects on the autistic child of an education shared between home and school, this study makes an original contribution to knowledge in this area.

### 2.5.3 Studies on 'flexi-schooling'

There is little research literature available on flexi-schooling in the UK. The Centre for British Teachers (CfBT) Trust published a report, 'Flexi-schooling – How One School Does It Well' (Gutherson & Mountford-lees, 2011) in which it articulates both potential benefits and disadvantages of the practice (p. 29):

#### **Benefits:**

Flexibility helps retain children within the system

Offers a phased approach to reintegration

Offers support and encouragement to home-schooling families

Enables greater levels of personalisation whilst delivering the national curriculum

Enables education to be an 'anytime-anywhere' experience

Enables the creation of purposeful links between homes, communities and multiple sites of learning

May lead to higher development of competences such as critical thinking, researching, using computers, learning independently, problem-solving, creative thinking, decision-making, and time management

Enables access to specialist support

Any resources designed to support flexi-schooling families can also be beneficial to all

#### **Disadvantages:**

Impact on teaching staff – time and professional development

Children may feel isolated and parents may have concerns about children's social development

May impede accurate and appropriate assessment of learning

Funding



families attending the school

*Figure 2: Summary of advantages and disadvantages of flexi-schooling (CfBT)*

Although this summary is useful, the CfBT report refers only to the practices in one small, rural primary school. It reflects how flexi-schooling has been arranged at this one school, rather than on the practice of sharing education between home and other schools specifically to meet the needs of a child with autism.

Collins, whilst citing this study's author (Lawrence, 2012) as describing this model in the UK, suggests that no research has been found indicating that flexi-schooling has yet been applied in South Africa (Collins, 2014), and Hurlbutt again cites Lawrence (2012) to identify how 'specific interests, skills and passions ... are harder to cultivate in school' (Hurlbutt, 2012, p. 2). Of significance is a recent quantitative study (Schafer & Khan, 2016) which uses data from the United States National Household Education Survey: Parent and Family Involvement (NHES-PFI) of 2012 to examine prevalence of flexi-schooling, and to make statistical comparison between school enrolment, full-time home-education and flexi-schooling.

This study describes flexi-schooling as 'an approach involving at least some instruction both at home and at school' (Schafer & Khan, p. 2). It is published in 'Rural Sociology', and is concerned with tracing many factors which influence decisions to enrol pupils, to home-education or to flexi-school, including factors as diverse as urban versus rural factors, economic factors, ethnicity, number of children in the household, parents' working profile, years living at address and the location within the United States. Amongst these factors is disability, which is identified as potentially having 'particularly important interactions with other family and locational factors' (Schafer &

Khan, 2016, p. 3). They identify, again citing this study's author (Lawrence, 2012) that disability status may have important interaction with other factors, that parents of children with disabilities may choose flexi-schooling because of concerns about the capacity of schools and teachers to meet their children's specific needs and that flexi-schooling may be an attractive option for parents who perceive that they can meet some of their child's needs (Lawrence, 2012, in Schafer & Khan, 2016). Their research gives some data on the respective prevalence of school enrolment, home-education and flexi-schooling in the US, suggesting that of the 17,563 responses made to the NHES-PFI 2012 survey, 363 were flexi-schooled, representing over 2% of the school-aged population and in fact exceeding those who were fully home-educated (1.8%). Parents who identified as flexi-schooling reported attending school events, communicating with school through the use of email and attending parent/teacher conferences.

Where some 20% of enrolled students in the US are reported to have disabilities, with a similar percentage reported in home-educated students, almost 30% of flexi-schooled students were reported in Schafer and Khan's study to have disabilities, a difference which is 'nearly statistically significant' (Schafer & Khan, 2016). Of note also is that racially and ethnically, flexi-schooling students were very similar to enrolled students, where home-educated students were over 85% white. Results suggest that a more economically and racially diverse section of the community view flexi-schooling as a viable option than do home-education, and that 'flexi-schooling plays an important role in the diversification of the homeschool movement according to race, class, and family factors' (Schafer & Khan, p. 19). Importantly for this study, the research suggests that most families currently identified as 'home-educating' in the US are more accurately involved in flexi-schooling, and that even those who are full-time home-educating have frequently previously been enrolled in school. The study argues for the

importance of flexi-schooling in expanding the range of educational options available to parents and suggests the further exploration of both the prevalence and implications of flexi-schooling. It suggests that it provides more generalisable support for qualitative studies (e.g. Lawrence, 2012) of how parents ensure that their children get the education that they need and deserve through a combination of at-home and school-based provision.

## **2.6 RESEARCH QUESTIONS**

Emerging from this review of current research are questions as to the perceptions of parents regarding their lived experiences of shared education between home and school with their autistic children, of their reasons for sharing that education and of their understanding of the benefits which it brings to their child. These questions include: are their perceptions similar to those of parents who home-educate their autistic children, and is there similarity between their lived experiences and that of parents sharing education between home and the school-outreach services of SIDE in Western Australia? How do the parents in this study understand the shared education which they experience, and how do they perceive 'benefit' within the context of that shared education? How do they describe their role as shared educators, and how do they understand their role as educators as it intersects with their role as parents? These questions, explored within the context of whether education shared between home and school can benefit the child with autism, are examined in this study using the qualitative approach of interpretative phenomenological analysis, as described in the next chapter.

## **2.7 CHAPTER SUMMARY**

This review of literature has considered shared education within the context of 'flexi-schooling', and within that of both full-time home-education and full-time school education. It has reviewed current understanding of autism, and specifically approaches

to education for autistic children. It has reviewed the importance of parental involvement in children's education, and identified how autism may be presenting a barrier to that involvement, further disadvantaging the autistic pupil. It has begun to highlight the possibility that sharing education between home and school may be both more widespread than it appears, and that it might be even more widely adopted were it to be made more 'visible' as an option.

This study investigates the self-perceived motivation for and understanding of shared education for their autistic child by five parents (all mothers) recruited through the on-line group Flexi-schooling Families. The philosophical and practical approach used to explore these parents' motivations and understanding is now discussed.

### **3 CHAPTER THREE: METHODOLOGY**

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This chapter describes the interpretative phenomenological analysis (IPA) methodological framework employed in this study. It articulates the value of utilising an interpretivist approach; given that there is no one 'right way' to educate children with autism available to be discovered (Parsons et al., 2011), and certainly no one 'right way' which would benefit all children with autism (Beardon, 2012), the study enables those involved in this shared education model to tell their own stories, construct their own meanings and define their own concepts of benefit. The study is exploratory, in that it asks questions about an under-researched phenomenon; it is descriptive in that it articulates what the participants are doing, and their perceptions as to why they are doing it, rather than being concerned with external measures of explanation, and it is interpretive in its exploration of the participants' experiences and their perspective on those experiences (Gray, 2013).

The chapter also discusses the positionality of the researcher and explores the advantages and challenges which being an 'insider' researcher bring to the study, together with the tensions which they bring to the chosen methodological framework. It articulates the rationale for the development of a theoretical postulate to bring transparency to the researcher's initial position and to her perspective in the 'meaning making' which IPA involves.

#### **3.1 RESEARCH APPROACH: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF IDIOGRAPHIC CASE STUDIES**

In addressing the questions raised at 2.6, this study adopts the epistemological position that an interpretative phenomenological analysis (IPA) approach will enable the gathering and interpretation of data able to inform the researcher about how the

participants in the study make sense of their involvement in shared education (Smith, Flowers & Larkin, 2009). IPA is a research approach which explores the lived experience of the subjects of a study (Tuohy et al., 2013). It is both a descriptive approach (eidetic), in that it is concerned with identifying how things are, and interpretive (hermeneutic), recognising the inevitability of interpretation both by the subject and by the researcher (Pietkiewicz & Smith, 2014). This form of qualitative research argues for the importance of understanding the meaning of experience, actions and events as they are interpreted by the participant (Henwood, 1996). As such, IPA has as its goal the investigation of how individuals make sense of their own experiences (Pietkiewicz & Smith, 2014). IPA draws on elements of the theories of eidetic experience as explored in phenomenology and of interpretative endeavour informed by hermeneutics (Pietkiewicz & Smith, 2014; Smith, Flowers & Larkin, 2009).

### **3.1.1 Phenomenology**

The concept of phenomenology, both as a philosophy and as a method of qualitative inquiry, emerges from the work of Edmund Husserl (1970). As such, it explores the eidetic (descriptive) experience of the individual, aiming to identify the essential components of an experience and what makes that experience different from other experiences (Pietkiewicz & Smith, 2014). Husserl argued that the individual must try to recognise the essential component of a phenomenon, 'bracketing out' attitudes and prejudices which influence beliefs and understanding (Tuohy et al., 2013). Central to the concept of phenomenology is that it focusses not on arguing a point or on developing a theory, but on revealing meaning (Flood, 2010).

A phenomenological approach to this study gives a focus on the nature of the shared education under scrutiny, yet the study's focus is less on the description of this phenomenon and more on the personal meaning and sense-making of the parents

involved in that shared education. Whilst it is a study of 'real-life' or 'life-world' experiences (Dowling, 2007), it is also interested in 'describing phenomena as they appear to the person experiencing the phenomena' (Tuohy et al., 2013). As such, IPA focusses less on describing the phenomenon as it appears and more on both the interpretation of that phenomenon by the observer, and of the interpretation of that 'sense-making' by the researcher. It accepts that the participants are 'experts in their own experiences' (Reid, Flowers and Larkin, 2005, p. 20), in this case as parents sharing the education of their autistic child between home and school.

### **3.1.2 Hermeneutics**

Interpretative phenomenology uses the development of Husserl's philosophy of phenomenology by Martin Heidegger (1962) into the area of hermeneutics, which argues that in order to translate another person's experience it is necessary to understand their mind-set and the language which they use to mediate their experience of the world (Pietkiewicz & Smith, 2014). In this sense the researcher must 'stand in the shoes' of their subject and use a dynamic process of interpretation to make sense of the subject's world. Heidegger introduced the concept of 'Dasein', meaning 'being there' to explore notions of consciousness, perception and awareness (Smith, Flowers, Larkin, 2009). In this way, any experience which is studied is subject to the concept of co-constitutionality (Flood, 2010), meaning that it is interpreted both by the subject, who makes meaning of his or her experience, and then by the researcher, who must de-code that meaning-making process (Pietkiewicz & Smith, 2014; Smith, 2007; Smith, Flowers & Larkin, 2009). This draws on Merleau-Ponty's philosophy that the researcher's sense of self remains holistic and can never entirely share the experience of the 'other' being researched (Merleau-Ponty, 1962; Smith, Flowers & Larkin, 2009). Values cannot be suspended in research of this kind, and these values will always mediate and shape what

is understood (Maykut & Morehouse, 1994). Since this study embraces the ontological position that there are multiple concepts of 'reality', it follows that it accepts that there can be no one objective interpretation of what is being studied; as a result, relationships between events and positions can be understood as multi-directional, and any explanations can be only be tentative (Maykut & Morehouse, 1994) and cannot be taken as fact (Reid, Flowers and Larkin, 2005). Where descriptive phenomenology relies on bracketing by the researcher to suspend his or her pre-suppositions, this bracketing is absent in IPA, as the researcher is part of the research (McConnell-Henry, Chapman, & Francis, 2009). Indeed, 'the researcher's previous understanding and knowledge ('fore-structure') helps interpretation' (Tuohy, 2013, p. 18).

This dialogue between researcher and participant can be further understood through the concept of the 'hermeneutic circle'. This involves the participant and the researcher sharing, interpreting, revisiting and co-constructing meaning. This circle is also concerned with the dynamic relationship which exists between the different elements which make up the data in a study, and the study as a gestalt whole (Smith, Flowers & Larkin, 2009). So, for example, the 'meaning of the word only becomes clear when seen in the context of the ... sentence ... [and] the meaning of the sentence depends upon the cumulative meanings of the ... words' (Smith, Flowers & Larkin, 2009, p. 28). The 'sense-making' process applies first to the participants, who articulate their interpretation of the experience of shared education with their autistic child, and then to the researcher who much make sense of their articulation. The participants in this study are each expert within their own experience (Tuohy et al., 2013), who share the sense-making of that experience in a dynamic dialogue with the researcher, who has her own parallel yet entirely separate experience of the same phenomenon of shared education with her autistic child. This position within this study can be viewed in a



similar way to that of Gudmannsdottir and Halldórsdóttir's Interpretative Phenomenological study of nursing home residents' experience of pain, where the participants were acknowledged as co-researchers in their personal experiential expertise, and discussions between them and researcher, engaging through the hermeneutic circle to identify the meaning or essence of the experience, led to their 'mutual construction of ... reality' (Gudmannsdottir & Halldórsdóttir 2009, in Tuohy et al., 2013, p. 20).

### **3.1.3 Idiographic Case Study**

The research approach of interpretative phenomenological analysis (IPA) adopted in this study is idiographic in that it is committed to the detailed examination of individual cases as unique (Smith, Flowers & Larkin, 2009). Idiography is a theoretical orientation posited by Wilhelm Windelband (1848-1915) which is concerned with the in-depth analysis of the singular case, the individual as unique as opposed to the individual as an exemplar of a population (Pietkiewicz & Smith, 2014). IPA employs idiography in so far as it focusses on how a particular experience is understood from the perspective of a particular person or people, within a particular context (Pietkiewicz & Smith, 2014; Smith, Flower & Larkin, 2009).

The case study, according to Yin (2013) is a research method that investigates a contemporary phenomenon within its real-life context. Thomas (2015) asserts that the case study is especially good for understanding the details of what is happening, for making connection and gaining insights. Although he acknowledges that in case studies the researcher is trading depth of coverage for depth of understanding, he suggests that potential explanations based on depth of understanding are what a case study does best relative to other kinds of research. Where many research methods are reductionist and are about reducing things, breaking them down and understanding them in terms of their

constituent parts, Thomas argues that the case study is different: it is gestalt (Thomas, 2015). The 'starting point taken in the case study....is that certain phenomena are more than the sum of their parts and have to be understood as a whole' (ibid., p. 46).

This study makes detailed case-by-case analysis and explores in detail the perceptions and understandings of five parents sharing the education of their autistic children. The intended outcome of this study is to 'give a voice' to the participants as individual examples of cases of shared education for children with autism. Each unit of study (case) is individual as each experience of a child with autism sharing education between home and school is different. Each case is therefore studied idiographically, as a discrete, self-contained entity. Each is illuminated to capture the perspectives of the participants and how their individual interpretation of meanings illuminate their experiences (Yin, 2013). As IPA is also interested in the examination of where the experience of each individual shares commonality with other individuals within the research focus (Reid, Flowers and Larkin, 2005), the study also makes synthesis across the idiographic cases.

A case study is a bounded unit (Thomas, 2015). The lived experiences captured in this study are bounded in a set period of time (approximately nine months from first interview contact to conclusion of data gathering). As such, each study draws on the parents' experiences up to that time but has a conclusion, providing a snapshot, a 'picture [which] presents itself as a whole over a defined timeframe' (Thomas, 2013, p153).

### **3.2 POSITIONALITY OF THE RESEARCHER**

IPA recognises the dynamic role of the researcher in recognising meanings made by the subjects, and in making meanings from that which is presented (Pietkiewicz and Smith, 2014). As part of this, it proposes that prior awareness (or 'pre-structure') is known or understood by the researcher before hermeneutic interpretation is made (Tuohy et al., 2013). Maykut and Morehouse (1994) postulate that researcher objectivity in any qualitative research is not possible as the knower cannot stand outside of what is to be known and values will always mediate and shape what is understood. The interactive nature of qualitative research means that the researcher must seek to understand what is meaningful for those that are studied, and, as such, the researcher cannot, and should not, seek to remain apart from those that are being studied (Maykut & Morehouse, 1994). Only through experiencing the world that is being studied in a similar way to the participant being studied ('indwelling'), they argue, can the researcher hope to recognise the complexities and connections before her. This *indwelt* or personal knowledge is both useful and necessary to IPA (Flood, 2010).

Researchers in the qualitative paradigm, and within IPA specifically, must use what they observe to construct versions of the world, and their own place within that world must be explicit (Maykut & Morehouse, 1994). In the case of this study into experiences of the shared education of children with autism, the researcher has shared the education of her own autistic child between home and school (and as such has 'lived' the position) for twelve years. As such, she may be seen to be an 'Insider Researcher' (Rooney, 2005); she is a practitioner within the field of sharing education for a child with autism and is also a member of the community of shared educators for children with autism, in that she has both written about and spoken on the subject. Furthermore, she is partisan to the emotional position that sharing education has indeed been of

benefit to her child with autism and, as such, brings to this study experiences, knowledge, understanding and emotional connection which it would not be possible for an 'outsider' to share. This position brings a number of potential benefits, including a greater understanding of the culture of what is being studied and an intimacy with it which promotes both the telling and the judging of 'truth' within that culture (Tedlock, 2000; Unluer, 2012), although it does mean that the researcher in this study cannot and does not claim objectivity.

Explanations, considerations and interpretations as framed by the participants are actively considered in this study by the researcher, employing elements of auto-ethnography and complete-member ethnography (Rooney, 2005; Ellis, 2004; Ellis, Adams & Bochner, 2011; Ellis & Bochner, 2000 – and see section 3.2 in this study). As an insider researcher, she is interested in a research methodology able to utilise her dynamic role in both recognising meanings made by the participants in this study, and in making meanings from what those participants present to her (Pietkiewicz & Smith, 2014). IPA allows her position as a complete-member researcher, able to share the experience of being a mother to an autistic child and of sharing that child's education between home and school, to be acknowledged as 'pre-structure' (Tuohy et al., 2013), understood and utilised by her both before and during the dynamic interpretative process of data collection and analysis.

The design of this study is thus built on the researcher's tacit knowledge. Leech suggests that 'What you want to know determines which questions you will ask. What you already know will determine how you ask them' (Leech, 2002, p. 665). In framing the questions for this study the researcher draws on her personal understanding of the experience of the shared education of a child with autism. The validation for case study

research comes, according to Thomas (2015) from the connections and insights made between the experiences of the researcher and those of the participants whose experiences are being explored. It is the connectedness between the experiences of having a child with autism, and with sharing that child's education, which informs this study.

### **3.2.1 Auto-ethnography**

Inherent in the meaning-making regarding the narratives which emerge from the cases studied in this research is the researcher's shared experience with the participants. As such, although not intrinsically auto-ethnographic, this study employs elements of auto-ethnography. Auto-ethnography is an approach to research that seeks to use personal experience ('auto') to understand cultural experience ('ethno') and to describe this through systematic analysis ('graphy') (Ellis, 2004). As such it uses autobiographical experience to illuminate and explore wider cultural and social experience and uses reflexivity to position the researcher within that which is being researched. In it the boundaries between researcher and researched become blurred as the researcher becomes the subject of her own research. It is a method which aims to use personal experience to produce meaningful, accessible and evocative research (Ellis, Adams & Bochner, 2011).

The research study described in this thesis is grounded in personal experience. That personal experience, of sharing the education of an autistic child between home and school, assumes something of the role of an 'instrumental' auto-ethnographic case study (Stake, 1995); it has examined the single case of the researcher's own experience in depth, as reported in previous publications (Lawrence, 2008, 2012). Although the researcher does not position herself as the 'subject' of this current research, and therefore both overt reflexivity on her practice and further articulation of the practicalities of what

she has done are inappropriate, the auto-ethnography reflection of the lived experience background has created a theoretical postulate around which to build the current study design. This postulate is expressed in nine theoretical propositions which articulate why, in the researcher's experience of it, she believes that shared education may have been of benefit to her son. Auto-ethnography provided an articulation of the validity for the researcher's position within this study.

For auto-ethnographers, validity means that a work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible, a feeling that what has been represented could be true (Ellis 2004 pp 9-10).

The researcher's experience of shared education with her own son gives her a position where she is strongly placed to identify lifelike, believable and possible experiences as described by the participants in this research. This goes beyond the question of whether what they report is accurate; given the vagaries of human memory, much may not actually be so in an historical sense. What it does give is a sense of the 'verisimilitude' of what is said. This relates to her competency as a researcher. Bochner (2002) challenges the researcher to question both whether the participant has had the experiences described, and whether the participant believes that this is actually what happened? The researcher's competency in this study is enhanced by her previous auto-biographical reflection. She has described her account of her experiences (Lawrence, 2012), and has considered their context, relevance and 'truth'; this gives her a sound base from which to consider the biographical narratives of the participants in this study.

A strength of auto-ethnography is its emphasis on research as story rather than theory (Bochner, 1994). IPA aims to capture personal and human dimensions of experience (Costantino, Clandinin, Connelly & Kushner, 2001). Stories include

subjective meanings, a sense of self and of self-identity (Etherington, 2013) and help to make sense of the ambiguity and complexity inherent in human lives (Bruner, 1997). Auto-ethnography enables the researcher to take her personal narrative (her autobiographical story of shared education with her autistic child) and to position it within the social culture of other parents sharing the education of their autistic children. As such, the researcher's experience illuminates, even creates the frame of reference for, this social culture. Her story is examined in the context of the story of 'others', and their stories examined in the context of her own (Chuang, 2015). Her auto-biographical account gives a foundation for her auto-ethnographic reflection and reflection of her own experiences, as captured using a complete-member ethnographic approach (Ellis & Bochner, 2000), and provide a 'lens' through which to study the experience of the other parents taking part in this study.

### **3.2.2 Complete-member ethnography**

The term complete-member ethnography (CME) was adopted by Ellis and Bochner (2000) in echo of the suggestion by Adler and Adler (1987) that ethnographers might assume a 'complete-membership role' in the community they are studying, and was used by Ellis and Bochner as a term to describe researchers who 'explore groups of which they already are members' (2000, p.740). CME enables the researcher to engage reflexively on his or her own lived experience, and as such has strong association with auto-ethnography (Chuang, 2015). CME and auto-ethnography are both interested in ways that the researcher's sense of self impacts on her sense of others; CME additionally requires that the researcher's sense of identity, at least within that which is being researched, is shared with the subjects of that research (Chuang, 2015). In this study, both the researcher and the researched share the central identity of being mothers of autistic children, and both researcher and researched are aware of that shared central

identity. The researcher is making an in-depth exploration of a group of people of which she is a full member (McDonald & Lopes, 2014) and the shared identity, history and perspective of being a full member of that group are central elements of that research (Chuang, 2015).

### **3.3 THE ROLE OF THEORETICAL PROPOSITIONS WITHIN THE RESEARCH DESIGN**

Yin advocates that 'some theory development prior to the collection of any case study is desirable' (2013, p.38). Theory development in this study can be articulated in a theoretical postulate which reflects the researcher's auto-ethnographic understanding of her central research question, and is informed by her reading of research literature. This theoretical postulate helps to frame the study, to scaffold its design and to identify both what data to collect and how to collect it. It directs attention 'to something that should be examined within the scope of the study' (Yin, 2013, p. 30) and indicates to the researcher where to look within the study.

Yin says, 'Only if you are forced to state some propositions will you move in the right direction. (ibid., p. 30). The researcher's postulate as to why shared education may benefit her child with autism emerges through understanding of the difficulties of the child with autism at full-time school as articulated in the literature and through observation of her own child, the ways that she believes these difficulties may have been relieved through education delivered at home and the advantages to her child of maintaining the link with school rather than opting for full-time EHE. This postulate has been informed throughout the fourteen years since the researcher's son received a diagnosis and the twelve years that he has shared his education between home and school, through experience, by reading, studying at graduate and postgraduate level, by attending conferences, by talking to teachers and other educators, by talking to other



parents and by observing other children with autism, and through listening to reflections by adults with autism on their experiences of school. The result remains a personal perspective (as one informed by an auto-ethnographic perspective must, by definition, be), but it is additionally one that can be articulated through both explicit and tacit knowledge. The ideas which inform the postulate are grouped into three areas. The first two of these, 'Experience of Autism' and 'Curriculum Content', emerge both from the researcher's reflection on her own experience and from her reading of the literature on the challenges of education for children with autism. The third, 'Parental Values', emerges equally from her own experience but also more directly from her contact over fourteen years with other parents of autistic children (see figure 3).

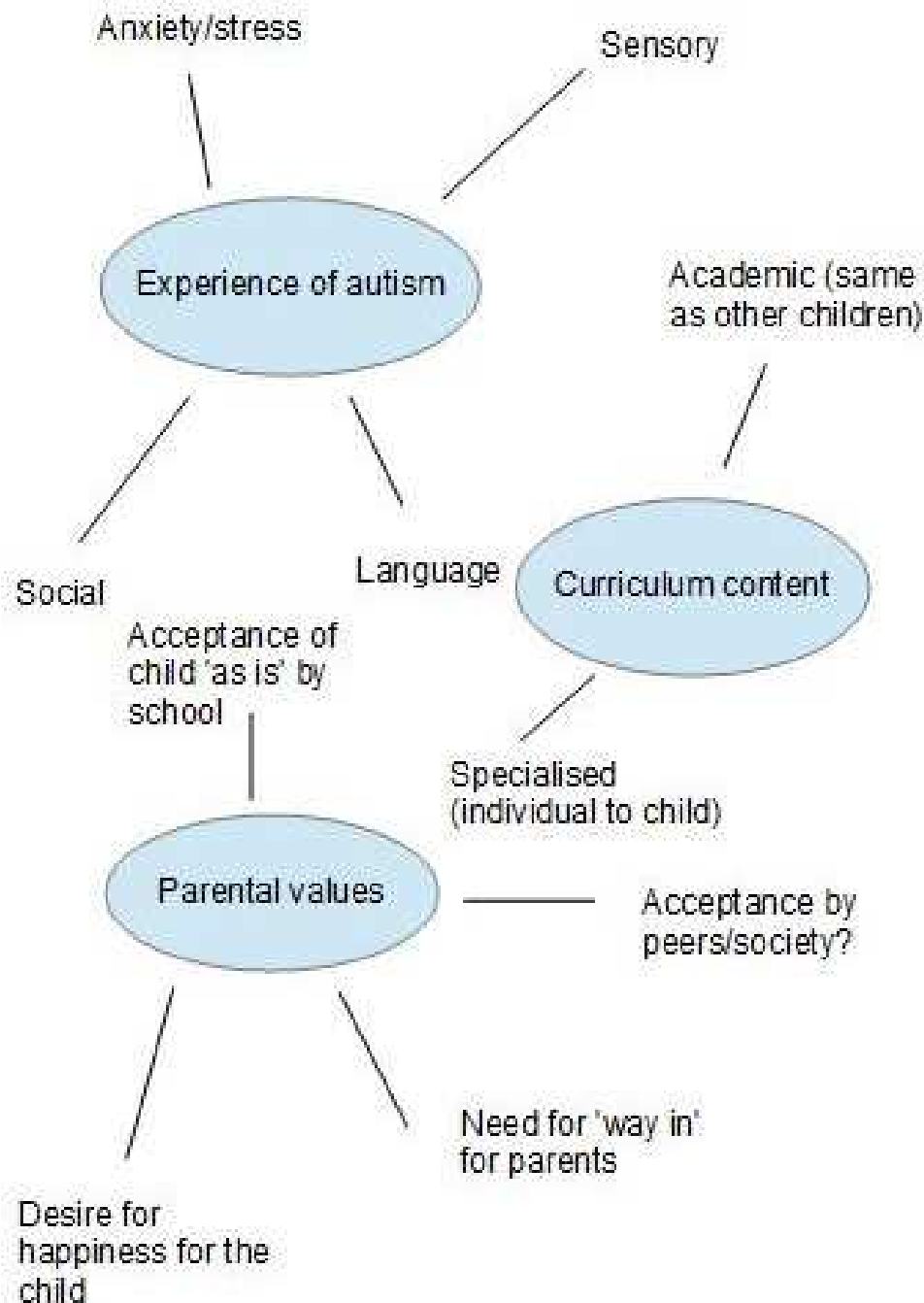


Figure 3: Areas which inform research postulate

The experience of autism area includes issues as understood from the perspective of the child, including sensory differences and the processing of language, and experienced by the child, including bullying and lack of autonomy. It also reflects something of how autism in the child may be experienced by those around the child –

by parents and school – as reflected in how autism presents in the child. Autism is not behaviour, but the window into the child's experience of autism is through behaviour (Attwood, 2003). Awareness of sensory sensitivity can lead to better understanding of sensory avoidant or seeking behaviours in the child, and awareness of language issues helps the adults around the child to be sensitive to misunderstandings and lack of communication. Each of these in turn may help improve awareness of anxiety and distress in the autistic child and in how that is communicated, and of the implication of this for social interaction (or avoidance) and social communication.

The curriculum content – the 'what education is' – part of the theory postulate map explores the tension in the demands on the autistic child's time between accessing the usual academic curriculum experienced by other children and the need for a specialised curriculum, individualised to the needs of that child. It includes the supports that are needed to be put in place to enable the autistic child to access the 'usual' curriculum and to engage with the academic curriculum at a level suitable to his or her intellectual potential rather than at a level of performance. It also considers what other learning the child with autism needs. These needs may include specific curricula such as those around sensory management, speech and language pragmatics or social skills, wider life skills such as road safety, queueing or orientation around the school or community, or they might include support with self-awareness, self-regulation and self-knowledge as the child learns how to understand, manage and appreciate his or her own autism.

The final section around the postulate for how shared education may benefit the child with autism considers the parents' perspective, particularly what the parents may 'want'. The researcher's experience has been that she, as a parent, wanted the school to

refrain from attempts to change her son or to 'train him' to hide his autism. She was keen always to work with adults who accepted him, and liked him, for himself, autism and all. This is a perspective which the researcher has had articulated to her in various ways by parents talking about education for their autistic child and is one that she felt was important to reflect in the design of this study. Equally important to parents though, although apparently contradictory, is that parents believe that school might help their children with autism to 'fit in' socially and to learn social skills through peer interaction that will enable them to integrate into the wider community. This apparent dichotomy may be part of the stress felt by parents of children with autism around their schooling. Also, important as an element of shared education to the research was the concept of using this extra at-home time as a way to improve interaction with her son. Part of the pressure on parents to get an early diagnosis for their child is the impression (reinforced by studies such as Pickles et al., 2016) that only while the child is pre-school will there be time, opportunity or support available for them to work with their child to increase communication and understanding. Finally, essential to the postulate is that the researcher was responding to her innate need to make her child happier, or indeed less unhappy. Leaving a child at school each day when he or she is either distressed, or is completely withdrawn from the situation, is distressing for the parent, and potential relief from this distress may be a central trigger for the introduction of shared education. This may be in response to reaching a 'crisis point', where actively stepping into their child's education may be the perceived only option for parents (McDonald, 2010).

This postulate around the benefits of shared education for the child with autism is examined more closely and articulated more precisely in nine theoretical propositions.

### **3.3.1 Theoretical Propositions**

The propositions, proceeding from the lived experience of the complete-member researcher, emerge additionally from understanding of the literature as discussed (this thesis, 2.2.2). They are:

#### ***3.3.1.1 Element one: Experience of autism***

The first four propositions explore ‘within child’ elements which may suggest a rationale for a shared education approach.

**Proposition 1:** Shared education may address issues of sensory processing differences in the autistic child (for example, Wing, 1979; Hermelin and O’Connor, 1970; Jones, Quigley & Huws, 2003; Iarocci & McDonald, 2006; Leekam et al., 2007; Grandin, 2000; Jackson, 2002; Williams, 1998; Bogdashina 2001, 2016; Jones et al., 2003; Little et al., 2015; Ausderau et al., 2014).

**Proposition 2:** Shared education may address issues of language processing differences in the autistic child (for example, Van Bergeijk, Klin & Volkmar, 2008; Attwood, 2007; Swineford, Baird, Thurm, Swedo, & Wetherby, 2014; Mandy & Skuse, 2008; Jackson, 2002; Sainsbury, 2000).

**Proposition 3:** Shared education may address the challenges to social acceptance, and particularly the experience of bullying, experienced by many children with autism (for example, Attwood, 2007; Ochs et al., 2001; Cappadocia, Weiss & Pepler, 2012; Hebron & Humphrey, 2013; Kelly et al., 2008; Chamberlain, Kasari & Rotheram-fuller, 2007; Rotheram-fuller, Kasari, Chamberlain, & Locke, 2010).

**Proposition 4:** Shared education may reduce the anxiety experienced by many children with autism (for example, Sukhodolsky et al., 2008; Van Bergeijk, 2008; Ghaziuddin, 2005; Matson & Williams, 2014; Jackson, 2002; Chandrasekhar & Sikich, 2015; Rieski, Matson et al., 2015; Ghaziuddin, 2005; Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998; Mayes, Gorman, Hillwig-Garcia & Syed, 2013).

#### ***3.3.1.2 Element two: Curriculum content***

These identify ways that the researcher believes that shared education is a way of enhancing the education curriculum for the child with autism.

**Proposition 5:** Shared education may allow the autistic child to better access the academic content of school, overcoming the barriers to academic attainment which may be experienced (for example, Ashburner, Ziviani & Roger, 2008; Estes, Rivera, Bryan, Cali & Dawson, 2011; Keen, Webster & Ridley, 2016; Plavnick & Hume, 2013; Fleury et al., 2014; Zandt, Prior & Kyrios, 2007).

**Proposition 6:** Shared education may increase opportunity to access specialist support not available in school such as occupational therapy, support from mental health specialists and speech and language specialists and support with functional and daily living identified as important (for example, NAS, 2011; 2015).

#### ***3.3.1.3 Element three: Parental values***

These identify ways that parents may believe shared education provides support, based on their own perceptions. These are based both on personal experience, and on anecdotal report collected informally during interactions with parents of autistic

children which have taken place during the fourteen years since the researcher's son received a diagnosis.

**Proposition 7:** Shared education is respectful of the autistic difference in the child and does not support a 'normalisation' process (rejection of the child as 'is') which may be perceived as occurring in school. There has been some limited research on the importance of parents' acceptance of their child's autism (for example, Futagi & Yamamoto, 2002; Midence & O'Neill, 1999; Jones, Hastings, Totsika, Keane & Rhule, 2014), which stresses its importance for psychological well-being. Shared education may allow for, or recognise, greater acceptance of the child, and consequently may support the development of self-identity and self-esteem in both parent and child.

**Proposition 8:** Shared education may enable a 'way in' for parents struggling to connect with their autistic child. Parental anecdotal report of their child as 'unreachable', 'in his own world' or 'in a bubble of autism' suggest the pain felt by parents struggling to connect with their autistic son or daughter. Shared education may give both time and structure to this interaction, mimicking some of the strengths of family-based approaches (for example, Thompson, & McFerran, 2015; Peckett, MacCallum, & Knibbs, 2016). It may give opportunity for the parent to follow the child's lead and to join in special interests. It may also be therapeutic for parents suffering pressures to mental health caused by their child's autism. There is evidence to suggest that parents of autistic children are at increased risk of psychological difficulties (for example, Bromley et al, 2004), and that the parent (specifically the mother)'s perceived locus of control is a significant factor influencing adjustment to the stress of raising an autistic

child (Henderson & Vandenberg, 1992). The simple matter of 'doing something' may relieve some of the distress felt by parents of autistic children who are aware of their child's unhappiness (Mills, Reiss & Dombeck, 2008).

**Proposition 9:** Shared education may be perceived to increase happiness and reduce unhappiness in the child and – correspondingly – in the wider family. Depression may occur in as high as a third of the autistic population (Ghaziuddin, 2005; Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998; Wing, 1990) and research suggests that suicidal ideation and attempts are significantly higher in autism than the norm (Mayes, Gorman, Hillwig-Garcia & Syed, 2013). In this environment, the possibility of parents' perception that their child is 'happier' (or 'less unhappy') when sharing education between home and school merits consideration. Additionally, parents of children with autism report greater levels of depression (Benson, 2006) higher stress (Olsson & Hwang, 2001) and lower over-all feelings of well-being (Ekas et al., 2009; Ekas et al., 2010). Ekas et al. (2010) identify that negative aspects such as depression and stress and positive influences such as life-satisfaction and psychological well-being 'may be separate dimensions with different influences' (p. 1275). In this way, even if stress and depression caused by autism in the child are not reduced by shared education, and even if characteristics of autism are not reduced, increased happiness (and reduced unhappiness) in the autistic child with a corresponding effect on the wider family may nevertheless increase life satisfaction and general well-being.

These nine propositions articulate the researcher's theory development, derived both from review of research literature and from her tacit knowledge gained through indwelling, and so inform this study's data-gathering strategies.



### **3.4 CHAPTER SUMMARY**

This chapter has articulated the methodological framework chosen for this study and explored why the use of IPA is considered appropriate for researching what parents of autistic children sharing education of their child between home and school understand to be the benefits of that shared education. It discusses the tension which the researcher's insider position may bring to the methodological framework of the study and explores how the articulation of theoretical propositions may provide transparency regarding the researcher's position.

## 4 CHAPTER FOUR: METHOD

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### 4.1 PARTICIPANTS

Participants for this study were selected purposively through the online Facebook group 'Flexi-schooling Families UK'. This group is 'closed', in that members are required to join in order to see or make posts, and these posts are moderated by the group managers. The group is described as 'strictly for families only; a place to discuss flexi-schooling and meet people who do it.' Permission from the group moderators was gained before request for volunteers to this study was made.

Participants in IPA research should 'engage with the interviewer and show a willingness to express their experiences and opinions' (Reid, Flowers & Larkin, 2005, p. 22). Participants drawn as volunteers from a flexi-schooling forum were likely to reflect this, and reflected a perspective as opposed to a population (Smith, Flowers & Larkin, 2009). Since it is the particular experience of sharing education between home and school with children with autism which is being researched in this study, the participants were selected on the basis that they hold a particular perspective on this shared education, that it may or may not be of benefit to their child with autism (Smith, Flowers & Larkin, 2009), and are happy to share that perspective. As it uses an idiographic approach, the sample size in this study is small, in line with IPA recommendations (Smith, 2004; Reid, Flowers and Larkin, 2005; Smith, Flowers and Larkin, 2009). It consists of five parents (all mothers) of six autistic children, who are sharing, or who have until very recently shared, the education of their child or children between home and school.

The Facebook group is for parents involved in, or considering, 'flexi-schooling' (education shared between school and home) for a variety of reasons, and the researcher

was aware that amongst the members are those who do so because their child has autism. The researcher's book, 'Autism and Flexi-schooling' (Lawrence, 2012) has been cited, discussed and recommended through the group, and she has been invited to comment on, and contribute to, the group on several occasions. The group therefore gave her access to parents who were sharing their autistic child's education, and also gave her an element of 'credibility' as the researcher carrying out the study. Her endorsement of 'Shared Education' (the term used for this study in preference to 'flexi-schooling' as discussed in chapter two) meant that her research outlook was not, at any time, positioned as neutral. It is accepted that she has a child with autism and that she has been involved as a parent in sharing this child's education between home and school. It is also accepted that she is a qualified mainstream teacher. Issues to do with the impact which the known status of the researcher may have had on the study are discussed in part 3.2.

Members of the Flexi-schooling Families group were invited to express an interest in becoming involved in this study through responding to an online post and/or by visiting the researcher's website. Response to initial enquiry was by email, requesting that the person confirm that they met the criteria of shared home/school education and a diagnosis of an autistic spectrum condition for their child given by a recognised health professional, and inviting them to read the Further Information Sheet (see Appendix 1) which formed the briefing aspect of the study. They were also invited to sign and return the Consent Form (see Appendix 2) if they wished to proceed.

In total, interest in the study was received from nineteen potential participants. Of these, eleven either did not meet the criteria (because they were only considering shared education and did not have experience of it at time of application), or failed to

return the consent form after the information sheet had been sent. This left eight potential participants. One of these chose not to proceed after she withdrew her son from school completely before data-gathering began, and one chose not to proceed after she accepted a full-time place for her son at a special school. A third, although sharing education between home and school, was using an external ABA provider for his at-home provision. After some discussion with this potential participant the decision was made that this provision did not fit this research criteria of this study as, although the education was taking place geographically 'at home', it was not being delivered by the parents nor did it deliver content decided by the parents. As such it did not involve the increased parental involvement inherent in the understanding of the 'at home' element of shared education as explored in this study.

The five boys and one girl whose parents took part in this study ranged in age from 5 – 14 years. All the participating parents are mothers.

#### **4.1.1 CY and Coby**

CY's son Coby, 10, was diagnosed with autism at age 7. He attends a mainstream primary school for four days a week. On Wednesdays, he is educated at home. This home-based education includes a two-hour input from LL, a qualified teacher appointed by the family, and the remainder of the time is spent in informal education with his mother.

#### **4.1.2 DN and Ben**

DN's son Ben, 12, was diagnosed with autism at age 4. He attends a mainstream secondary school with autism unit attached for one hour, twice a week. The rest of the time he is home-educated by his mother.

#### **4.1.3 GE and Adpar**

GE's son Adpar, 7, was diagnosed with autism at age 6 and also had diagnoses of ADHD, Social Anxiety Disorder and 'possible PDA'. He attends a mainstream primary school for an hour and a half each day. The rest of the time he is home-educated by his mother, GE.

#### **4.1.4 TE and Elliot**

TE's son Elliot, 14, was diagnosed with autism at the age of 4. He had attended a small private 'alternative' school for four days a week, and on Wednesdays was home-educated by his mother TE. At the time of interview, he had just begun to attend full-time at a mainstream secondary school with a SpLD unit.

#### **4.1.5 SS and Edward/Eloise**

SS's son Edward, 7, was diagnosed with autism at age 2. He is currently non-verbal. He attends a non-autism-specific special school in the mornings and an autism centre founded by his mother in the afternoons. Previously he attended his local mainstream primary school in the mornings and was educated at home by his mother, together with a 1:1 TA who also supported him in school, in the afternoons.

Edward's sister Eloise, 5, was diagnosed with autism at age 2. She attends her local mainstream primary school in the mornings and her mother's autism unit in the afternoons.

### **4.2 DATA-GATHERING STRATEGIES**

Two strategies were used to collect data within this study. These were a semi-structured interview, and a questionnaire. These approaches are outlined in figure 4 (under).

| Strategy                  | Aim   | Sample  | Type of questions  | Method of analysis  |
|---------------------------|---|---|--|---|
| Semi-structured interview | To allow participants to articulate their narratives within the phenomenon of sharing education between home and school with their child/children with autism | Five parents (mothers) recruited via the closed-membership Facebook group, 'Flexi-schooling Families' | Open questions; sub-questions to probe for additional material                                   | Interpretative phenomenological analysis  |
| Questionnaire             | To verify articulation made by participants in strategy one; to examine cross-case synthesis  | Four of the five mothers from strategy one, plus one father, one grandfather and one tutor            | 'Agree/disagree/unsure' response to statements extracted from semi-structure interview responses | Quantitative as to the extent of agreement; qualitative in interpretation of comments added |

Figure 4: Data-gathering strategies employed in this study

#### 4.2.1 Strategy One: Semi-structured interview

The semi-structured interview was chosen as the initial medium of data gathering for this study, in line with IPA guidelines (Smith, Flowers & Larkin, 2009), as it is sufficiently structured to enable the researcher to address specific aspects of the research question while still leaving space for participants to offer new meanings (Galetta, 2013). The semi-structured interview enabled the participants to give their stories freely, with minimal direction from the researcher. In line with suggestions on good practice in IPA (Smith, 2007; Smith, Flowers & Larkin, 2009; Pietkiewicz & Smith, 2014), this involved the creation of a schedule to encourage the participants to feel at ease, to be open and expansive and to talk at length. The medium of the semi-structured interview enables participants to 'describe the meaning of experience for ... those who are socially marginalized or oppressed, as they construct stories ... about their

lives' (Maykut & Morehouse, 1994, p. 5). Some parents of children with autism in an educational context may be considered as marginalised as 'parents' contribution to ... partnerships and education ... [is] marginal, relative to professional view points' (Reed, 2009, p. 26). This study gives these parents of children with autism a voice. As such, the consideration of participants' individual stories, the opportunity which voicing these stories gives and the potential for meanings to emerge from the stories are all central to the study.

The design of the interview is made using IPA guidelines (Smith, Flowers & Larkin, 2009) and advice described by Galetta (2013). The questions are structured into three main parts. The opening section of the interview aims to settle the participant, to check levels of understanding and to ensure that consent has been given and that the participant is aware of his or her rights within the interview context. It aims to create space for the narrative to begin and to ground the content of what is described within the participant's experience (Galetta, 2013). The initial questions seek to confirm specifically that the consent forms have been signed, that the participant is happy with the recording, and with their rights to stop recording or to choose not to answer any questions, and that there is understanding that anonymity will be maintained in the transcription of the interview. The schedule allows for the reiteration that the interview is semi-structured, but confirms that the participant will have an opportunity to add anything that they have not covered at the end of the interview. The first introductory questions are:

How old was x when you got a diagnosis?

Who/what prompted that diagnosis?

How were his/her early experiences of school?

What made you decide to start sharing education?

The first two of these are factual, and are therefore designed to be non-threatening and 'easy' to answer. They aim to help to take the participant's thoughts back to before the shared education took place, setting the scene for the second pair of questions and giving the suggested 'space' to move into explanations for the decision.

The middle section of the interview includes questions of greater specificity designed to allow the researcher to attend to nuances in the narrative, to shift into questions that are more specific as they relate to the research question and to look back, where appropriate, to the participant's narrative material as it connects with specific questions (Galetta, 2013). This supports two central questions: How does the participant arrange shared education between home and school for their child with autism, and how does the participant believe that this meets their child's autism needs?

First to be explored are the practicalities of the shared education. Questions are:

How do you share his/her full-time education between home and school?

How does school communicate with you about what they have been doing there?

How do you communicate with school about what you have been doing at home? Has communication between you and the school altered since you have been sharing education?

The schedule then asks about consistency and continuity:



Have you used any particularly autism strategies or techniques at home during your shared time that you know they use at school? Would you like school to help you with any strategies?

Has the school adopted any particular strategies or techniques that you use at home? Would you like school to adopt any strategies?

There is one further question about the wider family:

What (if anything) do you think you, or the wider family, gain by sharing your son/daughter's education?

The concluding segment, constructed according to Galetta, revisits the opening narrative for important connections and moves towards closure (Galetta, 2013). This gives the opportunity to check that the participant is happy that they had covered all the points that they wish to, and also aims to give the opportunity for information about what is going to happen next in the study to be imparted.

Finally, the schedule thanks the participant for taking part and asks if she is happy to be contacted for the next stage of the research. The researcher is prompted to inform the participant that she will receive feedback on the study at its conclusion, which is likely to be between two and six years from the time of the interview, and to formally terminate the interview.

Each interview took approximately one hour. In order to respect the preferred communication style of the participants the interviews were conducted either face-to-face in the participant's home or in a place of their choosing, or via electronic exchange. Four participants chose to conduct the interview face-to-face and one chose that the

interview take place electronically through email exchange. Of the four who preferred face-to-face communication, three chose that this take place in their homes, and one in a neutral venue (the autism therapy centre which she had co-founded).

### **Transcription**

The recordings of the semi-structured interviews were transcribed verbatim as soon as possible after the event to allow the researcher to recall the context of what was said while the conversation was fresh in her mind. All recordings will be retained for the duration of the study.

Green suggests that, 'What is represented [in a transcript] is data constructed by a researcher for a particular purpose, not just talk written down' (1997, p. 172). As such, consideration was given both to what degree it was useful to record in the transcript non-verbal content such as pauses, non-verbal communication (laughter, sighing etc.) and inaudible and/or off topic material (for example, the content of an incoming mobile phone call).

Analysis in IPA aims to interpret the meaning of the content of accounts rather than to analyse language as seen in conversation analysis, and therefore does not require the detailed transcription of prosodic elements of the recording (Smith, Flowers & Larkin, 2009). The transcriptions in this study are reproduction of the words in the recording onto the page, retaining word order and adding punctuation as it is inferred and as it aids readability (Tilley, 2003). Indication of unvoiced pauses is retained through the use of ellipsis ('I have to work, and, I don't know... I can teach so much, but I couldn't commit to ... It's just not something I could do' - CY), but not indication for length of pause. Repetitions and 'false starts' are transcribed ('So he was - basically with psychology - basically, he's not good with tests. He doesn't - he finds it very, very - anything that has been time - to do with time restraints out of the window, basically' -

DN), as are fillers ('Several fixed-term exclusions and things like that so, yeah' - GE). However, non-verbal elements are only recorded when they were deemed to add significantly to meaning (as with GE's laugh to acknowledge the inconsistency of her rejection of help from the school) and non-standard pronunciation recorded only when it carried inherent meaning (for example, SS's use of the ironic 'Yers!' to indicate how she felt when doctors initially stated that her son was not autistic).

TE's transcript is copied across from her own typed words, as exchanged in email.

Some elements of the recordings were changed in transcription. These included the use of pseudonyms and the removal of identifying details including school names, the names of teachers and doctors and geographical references (see 4.3.5).

#### **4.2.2 Strategy Two: Questionnaire**

A questionnaire was chosen as the second medium of data gathering for this study. Although Smith, Flowers and Larkin (2009) caution against the 'bite-sized, box-ticking (p. 56) responses which may emerge from wide exposure to market research and popular questionnaires in magazines, in this instance the questionnaire gave a further opportunity for member-checking of data and interpretation of that data, and enabled the researcher to verify the consistency in the positions articulated by the participants in their initial interviews. It gave an opportunity to build on the rich data already gathered through the semi-structured interview, gave an opportunity to probe for cross-case synthesis of ideas, and gave participants a further opportunity to expand on their initial comments. It also gave the opportunity to expand the parameters of the research and to enable other participants to become involved in the study.

The parents, as primary participants in this research, acted as gatekeepers to deciding whether anyone else might be approached to take part. Invitation to do so was made by the parents, and, in total, a further four adults took part in the study. These were:

LL (Coby's tutor) – interview and response to questionnaire

EE (Edward and Eloise's key-worker) – questionnaire

GB (Coby's grandfather) – questionnaire

FY (Coby's father) – questionnaire

Teachers and other school professionals could only be recruited for the study through direct invitation by parent participants. In practice, this meant that none took part in this study. The decision to recruit only through direct invitation by parents, even at the (realised) risk of limiting the range of the data was because, in line with her ethical responsibility to do no harm, the researcher was sensitive to the issue that some parents were hesitant about anything that might 'rock the boat' of their child's provision. Parent participants were offered an Information for School Professionals sheet that could be forwarded to school staff at their discretion, and they were invited to give the school's contact details if they preferred. Initially, four of the five participants expressed that they might be happy for their child's school to be approached, although ultimately three of these withdrew that consent. The other gave the name and contact details of the class teacher who was sent the information and consent forms. However, although these were initially returned, this teacher later withdrew from the study as her head teacher did not give her permission to take part. The later widening of the study to

include 'others' familiar with the experience of shared education enabled input from a father, a grandfather and two professionals working with the children in the study.

### **Purpose of the questionnaire**

The questionnaire sought to clarify the following questions:

1. Do participants continue to agree with comments they made during their initial interview when these are reflected back to them (and, inherent in this, is the researcher's understanding of what they have said a correct interpretation)?
2. Do participants who indicate similar concepts agree with a consistent statement on that concept (and, inherent in this, is the researcher's understanding that comments are similar correct)?
3. Do participants who have not indicated a concept in the interview agree with it when prompted (i.e. is it something they believe but didn't say, or not something that they believe)?
4. Do participants want to clarify or add to comments made by themselves (or others) in interviews?
5. Do 'Interested Others' invited to comment agree with, or disagree with, the comments?

Strands that emerged after coding of the initial interviews (see 5.1) in two or more of the interviews were gathered together and sorted thematically into four provisional 'thematic areas': Needs of child; Challenges of schools; Issues of communication/response by parents; and Potential benefits both at-home and at-school.

### *Statements indicating needs of child*

The child with autism needs more 'down time' than the typical school day gives

The child may feign illness and/or actually become ill to avoid longer times at school

Time at home allows for the child to follow his own interests and develop his own coping strategies

Shorter time at school/more time at home can lead to a happier child – which has a positive effect on the whole family

Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way

The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism

Children with autism may lack the communication skills to indicate distress/lack of understanding, so parents need to be more fully involved in order to 'translate'

### *Statements indicating challenges of schools*

All children with autism present differently, and schools struggle to accommodate all the differences

Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs

Learning in school is not functional if it cannot translate for the autistic child to home/the outside world

Parents may have developed strategies that work, but which may be impractical to translate into school

Schools are not set up to support an academically able child with autism who has behavioural difficulties which disrupt other pupils' learning

Parents are frustrated if they feel that school is merely containing their child and that he is not learning

Schools may see an autistic melt-down as the problem rather than understanding the problems which lead to that melt-down

Types of assessment at school may not fairly reflect the understanding of the child with autism (over or under estimating understanding.)

### *Statements indicating issues of communication/response by parents*

Extra time at home allows for closer emotional bonds to develop between the child with autism and parents/family

Parents often become expert in their children's autism needs and this expertise should be recognised

Responsibility for a child with autism's special educational needs rests with the parents

Home-education can be tailored to meet the child's more specific needs

Parents of autistic children are in a position to see the 'bigger picture' of their child's development

It is hard for parents to provide the additional autism support necessary if the child is in school all day/exhausted when he comes home

Parents may be the only people who love/understand a child with autism; that acceptance may be essential for the child's self esteem

Parents are not sharing education through choice but because their child with autism is indicating (either verbally or through behaviour) that it is necessary

*Statements indicating potential benefits both at-home and at-school*

Time shared between home and school allows for the development of self-knowledge in the child

School may be able to suggest strategies that can be helpful at/translated to home

Shared education facilitates communication and continuity between home and school

Support time at home means the child can do better at school

Shared education allows for sharing of expertise, both home to school and school to home

Sharing education between home and school can benefit the child with autism

These statements, ordered randomly (appendix 5), were gathered into a questionnaire to be returned to the participants. There was no further indication given to participants as to which statements had emerged from their interview, and which from the interviews of others.

When considering how to collect data through questionnaire on the extent to which participants agreed with their own, or others', previous comments on shared education, the initial medium favoured was a Likert scale. Likert scales are 'ordinal scales [which] measure levels of agreement/disagreement' (McLeod, 2008). This would have allowed the researcher to quantify the degree of agreement of each

respondent to each statement and therefore, potentially, have enabled the gathering of more nuanced data.

However, the researcher was sensitive to the possibility of autism in the participants since autism is generally understood to have a genetic component. Whilst some autism is understood to occur as 'Simplex' autism (a case where the diagnosed individual is seen as a 'one-off', with no autism detectable in the wider family), it also occurs in so-called 'Multiplex' families, where several members of the family have autistic traits (Sebat et al, 2003). Within the participants in this study, although none of the participating parents themselves had an autism diagnosis, one participant self-identified as autistic (“Even though I am not diagnosed, I am probably somewhere there myself”) and a second gave some indication of self-identification (“I look at myself and think, 'Hmm, is that me?'”). Additionally, there were a number of indications of autism reported to occur in the wider families of the participants. Of the non-diagnosed children of participants, two were suggested as displaying 'autism traits' by the participant parent; one participant suggested 'autistic traits' in the diagnosed child's father, and three wider family members (a cousin, an uncle and a great-uncle) were suggested to have 'autistic characteristics'.

Given this prevalence, it was important in this study that data gathering be as 'autism friendly' as possible, in line with ‘precepts that inclusive research be ready to adopt a plurality of methods for data collection’ in response to the different needs of, in this case, autistic people (Stone & Priestley, 1996, p. 710). This had been allowed for in the provision of electronic, as opposed to face-to-face, collection of data through the initial interview (something which the participant who self-identified with autism chose to accept), and this sensitivity needed to be continued in the questionnaire design.



Autobiographical accounts (for example, Grandin, 2000), suggest that people with autism may have difficulty making decisions. Research carried out in 2012 reports, 'Participants with ASCs [Autism Spectrum Conditions] reported experiencing several problems in decision-making more frequently than the comparison group, and were more likely to report avoidance of decision-making' (Luke, Clare, Ring, Redley & Watson (2012, p.1). Asking participants to identify if they 'agree' or 'disagree' with a statement requires a one-stage decision. To ask - using a Likert scale - both whether they agree or disagree, and simultaneously to decide to what extent they agree or disagree, requires a two-stage response. This seemed to the researcher to be unacceptable in an 'autism-friendly' questionnaire.

The questionnaire, therefore, had just three options – 'agree', 'disagree' and 'unsure'. The third option of 'unsure' was necessary as some participants would not be able to give an 'agree' or 'disagree' response. Additionally, the questionnaire design provided an opportunity after each response to make a comment, thereby allowed for a fuller response or clarification should the participant choose to give it. Of the four primary participants who responded, three gave occasional additional comments, and one commented on each statement. Of the 'others' who responded, two gave several comments, one gave a comment to a single statement and one gave no additional comments.

The use of statements, as opposed to questions with a 'Yes', 'No', 'Unsure' response, was again designed to be respectful should participants be autistic. To be asked a question, for example, 'Do children with autism need more 'down time' than the typical school day gives?' is to ask without clear enquiry parameters. The question appears to probe for knowledge in the participant, which the participant may or may not

have. Does the question refer to research, and, if so, to which research? In contrast, the statement, 'The child with autism needs more 'down time' than the typical school day gives', followed by the options 'Agree', 'Disagree' or 'Unsure' indicates that the participant is being asked to state an opinion. This was clarified in this study in the rubric to the questionnaire. The participant was asked to indicate, “Whether you agree with the statement, disagree with the statement or are unsure.” The use of the second person pronoun 'you', further indicated that this is a matter of personal indication, not of dogma.

The questionnaire (appendix 6) was sent to each of the five participants, together with information sheets and consent forms to be used should they wish to include 'others' at this stage of the research. Four of the five had originally indicated that they were happy for their child's school to be approached, and this questionnaire gave them the opportunity, although in the event three of the four chose not to pass the questionnaire on to the school and the fourth was refused permission. However, in two of the cases (SS and CY) the participants passed the questionnaire (together with the information and consent forms) to 'others' – to Coby's tutor, father and grandfather in the case of CY, and to the children's key-worker in the case of SS.

#### **4.3 ETHICAL CONSIDERATIONS**

A number of ethical issues emerged during the design of this research study. Not least, the researcher's positions as an insider researcher (Unluer, 2012; Rooney, 2005) or complete-member ethnographer (Adler & Adler, 1987; Ellis & Bochner, 2000; Chuang, 2015) brought several potential issues. Specifically, the researcher needed to be aware of the following issues:

- That her insider position could impact on the participants' behaviour and responses
- That her tacit ('indwelt') knowledge could lead her to misinterpret data or to make assumptions
- That her emotional agenda – given her history sharing education with her own child – could lead her to misrepresent – or even subconsciously to distort – data

(Rooney, 2005)

In recognition of these potential issues, this research study is undertaken under the researcher's professional, rather than her legal, name. This enables her to accept 'ownership' of what she has previously articulated on the subject of shared education (or flexi-schooling). As the writer of the only published book on the subject of shared education and autism, and as a contributor to a number of publications, on-line forums and at conferences and events on the subject, she has been conscious throughout that her persona as Clare Lawrence could impact participants' behaviour and responses, and indeed influence which participants were willing to be recruited to the study. The decision to embrace this position, rather than attempt to shield herself from it, was made explicit when she sought permission from Professor Macaskill (private correspondence, 18<sup>th</sup> March, 2014) to undertake this study under her professional name on the understanding that undertaking the study under her legal name (and thereby hiding her identity as Clare Lawrence) would have been unethical. Instead, by embracing and making explicit her previous involvement in the subject, the researcher hoped to engender integrity and transparency in her dealings with participants.

#### **4.3.1 Potential Research Bias**

The issue of indwelt knowledge potentially leading to misinterpretation of data is a complex one. By definition, tacit knowledge has enabled the researcher to interpret

the narratives of the participants in this study in a way that would not have been possible to do as an 'outsider'. This issue is addressed, in part, through the use of 'researcher reflexivity', in which the researcher makes clear the personal beliefs, values and biases which may shape her inquiry (Creswell & Miller, 2000), articulated in the nine theoretical propositions articulated in this study (3.3.1). It is addressed additionally in this study in the request for input by a second coder for an extract of the data (see 5.6.4). This input confirmed that at one level both researchers interpreted similar parts of the data as significant. On another level, the tacit knowledge of the researcher (and indeed her level of autism understanding not shared by the second coder), led to some discrepancy in interpretation of motivation congruent with the position that multiple perspectives can exist in data of this kind (Pietkiewicz & Smith, 2014).

Finally, the emotional agenda of the researcher requires scrutiny. She had shared her son's education between home and school for twelve years (and, indeed, continues to do so) because of the belief that this is of benefit to him. This belief does not imply bias that she will believe that a similar benefit will be evident for all children with autism since, clearly, the 'heterogeneity of the [autistic] population is such that any such generalisation would be ... crass [and] misleading' (Beardon, 2012). What the researcher's emotional agenda does provide within this study is a connection with a vulnerable population; it could be argued that the participants in this study would not have felt able to be so open and honest in their narratives if they had not accepted a shared position, and a shared emotional connection, as fellow parent educators of autistic children.

Arguably, no research which relies on report by participants can fail to be affected by that participant's perspective at that captured moment in time, and equally,

interpretative phenomenological analysis will always include an element of subjectivism (Pietkiewicz & Smith, 2014). The aim in this study is to be transparent and open about the researcher's positionality, and thereby to enable readers to construct their own perspective (Creswell & Miller, 2000; Cohen, Manion & Morrison, 2000).

#### **4.3.2 Informed consent**

Prior to giving consent to take part in the study, all potential participants had the opportunity for private deliberation, to discuss the study with the researcher or with her supervisors if desired and to ask further questions. Participants were given details of how to raise queries or complaints with the supervisors and/or with the university ethics committee. Participants retained a copy of both the information sheet and consent form for future reference. All participants received regular feedback, opportunity for further input and update, and will also receive a summary of the research findings at the end of the research period.

The Nuremberg Code – Directives for Human Experimentation (1949) states that, 'The voluntary consent of the human subject is absolutely essential.' The Declaration of Helsinki (1996, in World Medical Association, 2009) states that, 'The subject [of non-clinical ... research] should be volunteers.' Central to the issue of gaining informed consent for this study, therefore, is the question, 'Who are the participants in this research?'

The primary subjects in this study are the parents who participated. The research was into their reasons for, and practices of, shared education for their child with autism. As such they volunteered to take part (i.e. participation was at their instigation, rather than at that of the researcher) and consent to take part in the research

was made by them, after due process to ensure understanding and that this consent could be seen as 'informed'.

These parents also acted as 'Gatekeepers' (Creswell & Plano Clark, 2007, p.175) for the involvement by other participants, particularly that of their children. At no time in this study did the researcher seek data directly from the children, and any input which the children gave came through the medium of the parents. In two cases the parents chose to conduct their own 'mini-interview' with their children and to relay the content of these to the researcher. Intrinsic to each of these was that the child gave permission for the researcher to receive and use the data, using the pseudonyms agreed. However, in order to ensure full and informed consent (and not just assumed consent) further confirmation was sought that each child was happy in these cases for their contributions to be cited. This was gained on 26/5/16 and 27/5/16.

On three of the occasions of the initial interview with the parent, the child was present for some or all of that interview. This was at the instigation of the parents. In these cases, although their responses were recorded, these responses were not used directly in the study as consent had not been gained from the child to use their input prior to the interview taking place.

Consent for data to be used about those who have not given overt consent (as opposed to collected from them) is a more difficult area. Coby, Ben and Adpar were each present during the initial interview data collection, were aware of the recording and could hear (and at times comment on – although this has not been used) what that data included. Discussion about the purpose and use of the data was made in each of these cases during the discussions on pseudonyms. In the case of Elliot, although he was not present at the initial phase, his awareness of the data-gathering could be seen through

his readiness to offer his own feedback (13/11/15) and his consent to use that data recorded through correspondence (26/5/16.) With Edward and Eloise, however, there was less clarity as they may not have been aware of their part in this study, and as such it was not possible to assume consent. Indeed, gaining informed consent for the use of data about Edward and Eloise raises challenges, both due to their ages and to their communicative abilities. Edward is 7, and is non-verbal. Eloise is 5, and has limited expressive language. Without their consent, there could be a danger that data could be understood as being intrusive on the children's privacy. One of the basic ethical principles of the Belmont Report (1978) is that, 'Persons with diminished autonomy are entitled to protection.' This study was therefore protective of their rights to privacy through the use of pseudonyms, by the removal of identifying details of them and their geographical location in the data, and through the fact that their schools were not contacted.

#### **4.3.3 Potential benefits to participants**

Participation in the study did not benefit participants directly, although having the opportunity to discuss the provision they are offering their child did seem to provide some satisfaction. Additionally, the very fact of taking part in the research may have given them some feeling of validity and support since this model of education may include feelings of isolation for the parents, and the opportunity to take part in the study, together with receipt of feedback from it, may give opportunity for further insight and understanding of the shared education model.

#### **4.3.4 Potential negative effects for participation**

Discussing anxieties about their autistic child's education was, for some participants, distressing, although this distress was intrinsic to their situation rather than being due to the act of discussion. It was made clear throughout the process of the

study that participants were free not to answer any questions should they wish, and to withdraw either from interview or from the research at any time. None of the participants formally withdrew from any aspect, although one participant became 'hard to reach' at the questionnaire phase of data gathering. The other participants remained enthusiastic and motivated throughout the lifetime of the study.

Involvement in the research required some demands made on participants' time, for the original interview, for the reading and approving of feedback and for the completion and dissemination of questionnaires. This was discussed prior to the commencement of each stage of the study and the freedom to withdraw reiterated at each point.

#### **4.3.5 Pseudonyms**

In line with the ethical assurance of confidentiality, all participants in the study were anonymised. In the case of adults, they are referred to by initials and in the case of children, through use of a pseudonym. This was discussed with each participant at the time of collecting informed consent, and further correspondence on the issue followed.

The decision to differentiate between adult participants and their children (through the use of initials for adults and of pseudonyms for children) was taken in order to clarify identification in the study and for it to be transparent to the reader when reference in the text is to an adult participant and when to their child. The decision to use initials for adult participants was made with the permission of the participants, with the proviso that initials might need to be changed if, for example, two participants had similar initials. In the event, the researcher indeed decided to change their initials for reasons of confidentiality, as indicated under.



The decision to use pseudonyms for the children rather than numbers or codes was made in a wish to maintain a respect for the human element of the narratives told. The study was with parents, and referring to their child as, for example 'Child A', could present as cold or distancing. Furthermore, it is important to allow ownership of the narratives by the participants (Grinyer, 2009). These were their stories, about their children, and it is important to retain personalisation and avoid clinical distancing. However, the choosing of pseudonyms is not without controversy (Grinyer, 2009).

A number of strategies were considered for choosing the pseudonym names for the child participants. These included using lists of the most popular names in the UK in the year of that child's birth, and the use of an online random baby name generator. Each of these strategies carried advantages, although each was ultimately rejected. The use of the most popular name by gender in the year of birth had the potential advantage of reflecting the age of the child. However, each of these was rejected as both a notion and as a strategy early in the study for purely personal reasons: the most popular boys' name in the year of birth of the first participant child was, in fact, the researcher's husband's name, and the researcher felt that this might give discussion of that child an unacceptable bias, even at a subconscious level. More prosaically, there was also the danger that two participants might share their year of birth. The random name generator would have had the advantage of being truly anonymous. The generator considered gave various options, including identifying 'Specific Origin' from the list English, Sanskrit, Latin, Arabic, Hebrew and Spanish, which would have allowed some personalisation by the participants. As an experiment, five male names were generated by the researcher using the 'English' origin option. These were: Frankin, Brandon, Winston, Colby and Denzel. However, the very 'random' nature of these names gave rise to ethical issues. None of the names could be guaranteed to be seen as neutral by

the participants; 'Winston' for example, is a name that might be argued to have specific racial cultural connotations as well as being heavily value-laden through its association with Winston Churchill.

In the researcher's complete-member, auto-ethnographical position within this research, she was aware that she would have found the imposition of a name onto her child in a study without reference to her own social, cultural and ethnic identity to be offensive. Indeed, throughout publication regarding the sharing of education with her son she has used a pseudonym, both for him and for herself. These were chosen by the researcher, after discussion with her husband and with her son. She was aware that this sensitivity as the parent of an autistic child may be shared with other participants in the study. Sinclair (2012) refers a perception of autism in parents that they may experience grief 'over the loss of the “normal” child [they] had hoped and expected to have.'

Although not all parents may be in this situation, the researcher for this study was aware of a responsibility not to further de-personalise participant's children, and inflicting a name other than the name given to that child at birth seemed, in this context, to be unethical. Additionally, self-identity and self-awareness may be considered major areas of difficulty in autism (Chiu et al., 2008). The issue of being identified by a name that is not that child's own for a child with autism, was something that needed careful consideration.

The researcher's preference was to discuss the issue of a pseudonym with the parent – and, if possible, with the child – and to reach a negotiated outcome.

### **CY and 'Coby'**

CY discussed the issue of a pseudonym with Coby, in the researcher's presence, before the interview began. He preferred initially to use his own name, but when the

reasons for “another” name were explained by his mother, he suggested the name Coby, giving specific reasons around the sound of the word.

### **DN and 'Ben'**

Ben's first response to the idea of a different name was, “That sounds scary.” He then immediately suggested, “Sarah. Sarah. Call me Sarah.” This raises interesting questions about perceptions of self and gender which, unfortunately, took the researcher by surprise. Her immediate response was, “The trouble with Sarah - and I could call you Sarah - but then they’re going to think you’re a girl and it’s easier for me if they know you’re a boy.” Ben then suggested his name, and when the researcher further queried whether he was happy with it, responded, “Ben’s good, yeah.” However, the researcher felt on reflection that she had not given his original suggestion a serious enough response. She followed this up in an email exchange with his mother, inquiring whether he was happy with the name Ben and confirming that she was ‘happy to use Sarah - or any name he chooses’ (email, 25/5/16). She replied (26/5/16), ‘He's fine with Ben.’

### **GE and 'Adpar'**

Adpar was initially very happy to give a pseudonym, as he uses one already to publish on YouTube. However, when this was referenced it became apparent that this meant that his position within the research would not be truly anonymous, since his YouTube videos feature not only his image but discussions about himself, his home and family and, additionally, give a geographical location. The researcher requested a change of pseudonym in an email exchange with his mother (25/11/15). She replied that he wished instead to use ' --- ', a choice which again might be traceable. Quoting the Statement of Ethical Practice of the British Psychological Association, Clark (2006) suggests that it is the researcher's responsibility to preempt potential breaches of

anonymity in data collected, writing, 'Where possible, threats to the confidentiality and anonymity of research data should be anticipated by the researcher' (p.3). Since additionally in the course of writing up the study it became apparent that four of the six children had names beginning with 'E', and that Adpar's choice and the pseudonym of another participant were visually easy to confuse, the researcher used this consideration to request, via email (25/5/16), that the spelling of Adpar's pseudonym be changed.

### **TE and 'Elliot'**

TE chose the pseudonym for her son as he was not present at the time. Her first suggestion was to use the initial 'E', but – when the wish to differentiate between adult and child participants through the use of full names for the children was explained, she suggested 'Elliot'. Elliot gives tacit consent to the name as his input is entitled 'Brief Interview with Elliot'.

### **SS and 'Edward' and 'Eloise'**

Neither child was present during the interview with SS, who chose these pseudonyms. The researcher had no interaction with the children to confirm whether they are happy to be known by these names in this study.

The researcher's openness with participants about anonymisation itself also merits further ethical considerations. Because the researcher has been transparent with the participants about their identification (initials) and that of their children (the agreed pseudonyms), this means that they will be able to identify themselves in the research findings. This engagement with the findings is actively encouraged through the process of validation and verification of data throughout this study. However, the researcher is aware also that participants would be able to identify themselves and/or their children in

the final thesis, and in any discussions, comments or future publications, and this is something to which she is sensitive.

Clark (2006) raises further issues regarding methodological and substantive issues of anonymisation. He considers whether anonymising can lead to issues regarding the archiving of research, or the traceability of research into further studies. He argues that by imposing pseudonyms or using initials to identify participants within a study, the researcher risks losing a deeper appreciation of relationality of data. Of further consideration is that, while in this study locations used to gather data have been anonymised and identifiable features such as school names have been removed, the participants were recruited initially through the same on-line forum. In this instance, this forum could itself be understood as a 'location'. The fact that the participants are all members of this forum does increase the risk that they may know of each other, and may interact with each other on the forum. The forum itself is 'closed' and is moderated by a third party, with participants asked to post using their own names rather than anonymised usernames. In this context, the use of their initials for participants does not provide complete confidentiality. In consideration of this, and in line with her responsibility to guard against any potential breaches of confidentiality, the researcher made the decision to further anonymise the participants, assigning random initials to them in place of their actual initials.

#### **4.4 CHAPTER SUMMARY**

This chapter has discussed the selection process used to recruit participants to this study, and articulated who those participants are. It has described the methods used to gather data and has considered the rationale for, and the presentation of, the two data-gathering strategies used, those of semi-structured interview and questionnaire.

Additionally, the various ethical issue arising during this study have been considered and explored. Approval for this research study was granted by the Ethics Committee at Sheffield Hallam University in March 2014 (see appendix 8).

## 5 CHAPTER FIVE: DATA ANALYSIS

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‘A successful [IPA] analysis is interpretative (and thus subjective) so the results are not given status of facts; transparent (grounded in example from the data) and plausible (to participants, co-analysts, supervisors, and general readers).’

[Reid, Flowers and Larkin, 2005, p. 20].

IPA provides guidelines for the analysis of data which are flexible and able to be adapted according to the needs of the individual researcher (Pietkiewicz and Smith, 2014). The researcher is encouraged to be ‘flexible and creative’ (ibid., p. 11) in her approach to the analysis of her data. In line with IPA's requirement that the researcher totally immerse herself in the data (Pietkiewicz & Smith, 2014; Smith, Flowers & Larkin, 2009) the recordings of the interviews were first listened to and the transcripts read and re-read several times before analysis proceeded. The purpose of this immersion is to ensure that the participant becomes the focus of the analysis and that the researcher is actively engaged with the data in order to enter the participant's world (Smith, Flowers & Larkin, 2009). The initial 'free textual analysis' (Smith and Osborn, 2007, p. 53) involves understanding, paraphrasing and interpreting the content of the interview to begin to identify what is ‘interesting or significant’ (Smith and Osborn, 2007, p. 67).

### 5.1 INITIAL ANALYSIS SUMMARY

The initial 'summary' analysis of each of the interviews in this study was written up into a short report, designed to reflect the interpretation of that interview back to each participant. This aimed to check that the content of what was said during the interview was correctly understood, and to ensure that this understanding of the data was sensitive

to the intention of the participants. This report included a statement made in the second person indicating the interpretation of what had been said during the interview and gave example quotes from the transcript to indicate how this interpretation had been made.

### **5.1.1 Example of analysis summary (SS)**

The following is an example of an extract of the analysis summary, returned for validation and verification to SS:

Sharing Edward and Eloise's education between home and school is something that you feel that you have had to argue hard to achieve, and that the school has not always fully understood. You feel frustrated that you believe bureaucracy and budgeting issues can sometimes be used to decide provision rather than looking at a child's individual needs. You feel that you have had to become an expert on your children's autism in order to get them what they need, and you feel also that you have been enabled to learn how to meet their needs though the experience of sharing their education. You are clear why you feel that some school-based education is valuable for your children, but are also clear why your children's autism needs cannot be met in a mainstream setting, even with additional support. You are clear why you feel your children's education has worked across the environments of school and home, and particularly why your own part in it has been an essential component. You feel that shared education has brought Edward and Eloise closer to you as well as improving their relationship with each other and with their grandparents, who are fully involved in their home programme. You believe also that the children's shared education has had advantages for the school and are confident about its benefits for your children, for you and for your family.

*Excerpts from interview which suggest content of summary:*

Sharing Edward and Eloise's education between home and school is something that SS feels she has had to argue hard to achieve. She feels that school has not always fully understood it, nor her children's needs:

They'd come to meetings ... and they'd sit there and would argue that home-schooling wasn't a good idea and we all needed to get him back to school ... there was always, 'We'll come to this so we can increase his hours', or, 'This will work to increase his hours'



[Eloise] is at XX school in the mornings and they already want to talk to me about her and increasing her hours at school because she's 'doing so well.'

Edward would sit ... in the same spot, all day long and not make a noise .... He wasn't running around, he wasn't hyperactive, he wasn't demanding of attention and he wasn't hitting other children. He was no trouble.

[School staff say] you need to be accessing this or accessing that – very blinkered.

I did find myself having to constantly justify ... the parameters of what we were doing.

No-one bats an eyelid if you've got a potential gymnast or athlete and they want to flexi-school, or someone who's doing a theatre production in the West End. Then it's, 'Oh yeah. Let them do it.' But as soon as you've got a child who positively, academically benefits from it, it's 'Oh, I don't know.'

[.../]

Feedback from participants on these summaries varied. CY gave a number of small clarifications, for example:

On page 5, the second question, “And do you have any communication with the 1.1 TA?” What I meant was, “...Yes I do. She is lovely. We only manage to have quick conversations, often in the corridor. She has her own autistic son” etc.

And again:

On page 8 under “...knowing that you can say to him, there’s only two days, or one day?” I feel that I should mention that [the home tutor] and ‘Coby’ don’t really blow stuff up the garden...but they do do a number of outdoors science projects!

DN's response to the summary was, 'All [is] looking good' and GE similarly was happy to confirm the summary as valid with, 'I've checked through the summary analysis and everything is fine as far as we're concerned.' TE clarified one point:

Only thing that does need changing is the wording – the way I phrased my reply on early school, “it was not a disaster. Which I was expecting”. Ambiguous. I was EXPECTING a disaster! So please change to “it was not the disaster that I was expecting” as I did in analysis document.

SS's response was, 'I have added a couple of comments but it's a very accurate summary.' These comments are additions to what she had said, rather than corrections of misunderstandings. So, for example, in response to the summary 'SS feels that school has not always fully understood shared education', SS comments, 'I would say the arguing came more from those representing the Local Authority which made the position of the school very "difficult".'

## **5.2 ANALYSIS THROUGH 'LENS' OF THEORETICAL PROPOSITIONS**

Analysis in IPA, according to Reid, Flowers and Larkin, relies on 'the process of people making sense of the world and their experiences, firstly for the participant, and secondly for the analyst' (2005, p. 20). Yin (2013) advocates that the theoretical propositions used both in the design of a study can also be used as a 'lens' for analysis. However, in this study, these two positions create some tension. IPA is an inductive approach which 'does not test hypotheses and prior assumptions are avoided' (Reid, Flowers and Larkin, 2005, p. 20). Consequently, the researcher in this study accepts the need to be transparent about the extent to which her tacit, pre-structural knowledge on the subject of shared education for the child with autism – her 'prior assumptions' – might influence the inductive analysis of her data.

Consequently, prior to the inductive, interpretive act of the hermeneutic circle of data analysis in IPA, where she makes sense of the sense that the participants make of their reflections, she first made analysis of how the data does or does not conform to her pre-knowledge, as articulated in the nine propositions which inform this study. This analysis enables the researcher's position regarding these propositions be made overt and for her orientation in the inductive process of data analysis to be transparent.

The transcripts were therefore analysed with reference to each of the propositions, to record to what extent the participants reflected the researcher's complete-member theorisation. This enabled the researcher to consider evidence of issues such as, for example, sensory and language processing difficulties, social acceptance, anxiety and depression, in line with her pre-structural knowledge. However, research into real-life situations is seldom as 'neat' as this would imply. The researcher's understanding of sensory processing and language differences, although reinforced through familiarity with autism literature, emerged through observation of her son. Nor was this observation removed or clinical; when her son did not cry or seek help when he had a pin stuck in his foot, when the doctor diagnosed severe ear-infection of which her son had given no indication, or when the researcher learned to set a timer to remind her son to drink as he would neither ask for water nor give any indication of thirst, these influenced the researcher's understanding of 'sensory and language processing differences in autism'.

Each of the children in this research project is different and will manifest autism differently, but for each parent there will be an on-going, 'real life' awareness of their child's autism needs. Analysis through the lens of the propositions enables this tacit understanding, shared as mothers of autistic children, to be foregrounded before the inductive and interpretive act of IPA analysis proceeds. Further examples of the ways that the data in this study mirrors the real life personal experiences of the researcher are discussed in section 6.2.

### **5.3 DEVELOPMENT OF EMERGENT THEMES**

Having made transparent analysis of the data in line with her initial theoretical propositions, the researcher felt enabled to approach the data for a more inductive,

interpretative analysis. Qualitative data 'are exceedingly complex and not readily convertible into standard measurable units' (Schatzman & Strauss, 1973 in Marshall & Rossman, 1999, p. 151). The concern in this study is with identifying participants' meaning, with identifying repeating strands and with ensuring that understanding of both what had been said and what was meant – the interpretation of participants' accounts – is accurate. The framework for IPA analysis as recommended by Smith Flowers and Larkin (2009) and Pietkiewicz and Smith (2014) suggests that as the researcher achieves full familiarity with the data through immersion, where notes are made and these are gradually worked into emergent themes.

Smith (2007) indicates that there are no rules about what elements in the data should be commented on, and Smith, Flowers and Larkin (2009) also make clear that there is 'no requirement ... to divide the text into meaning units and assign a comment to each unit' (p.83), each remark emphasising the creative aspect of the meaning-making process. Marshall and Rossman (1999) suggest that the analysis of the data should be guided by the research questions and related literature already discussed. The purpose of the analysis is to 'understand more about the phenomenon we are investigating' (Maykut & Morehouse, 1994, p126).

The interview transcripts were, therefore, visited and revisited in order that associations and connections could be made, and that 'similarities and differences, echoes, amplifications and contradictions' (Smith and Osborn, 2007, p. 67) could be identified. The initial notes and summary as reflected in the report to the participants, are now 'transformed into concise phrases' (ibid., p. 68) as codes. These in turn are compared and amalgamated into emergent themes (see appendix 3).

The drawing of codes from the data into themes involves active engagement with the hermeneutic circle (Smith, Flowers & Larkin, 2009), where the details of the text are understood in the context of the whole, and the whole examined from the perspective of individual comments and utterances. This is a creative process and, although the researcher follows guidelines, the interpretive act of making meaning of data ultimately 'remains mysterious' (Maykut & Morehouse, 1994., p153). The researcher must also remain aware that this process of bringing meaning is not without dangers. These include, according to Tomal (2010), making false comparisons, failing to identify the cause, failing to view the whole situation and failing to recognise hidden agendas. Nor is analysis of data the only objective. As well as analysis (taking things apart), Thomas (2015) advocates synthesis (putting together) of meaning. He suggests that the task of the researcher includes making more of the parts than each is on its own. This creative process needs to result in something that is 'meaningful to the reader' and which is about 'seeing relationships between ideas and seeing how they are connected, seeing where things fit together (and where they don't)' (Thomas, 2013, p. 274). In this research project this 'creative process' is applied in the construction of the Agreed Statement and in the articulation of the super-ordinate themes which emerge from the data, as discussed in chapter five.

Whitehead and McNiff describe this process in more detail, articulating the need to make an 'account of the data which is comprehensible, truthful, sincere and appropriate' (2006, p.141-144). In order to be comprehensible, they argue, the report should use accessible, unambiguous language which allows for the emergence of meanings. Claims and statements must be supported by authentic evidence if the report is to be truthful and sincere (Whitehead & McNiff, 2006). This provides that the researcher needs to avoid the temptation to present her interpretation as the only reality.

The process of coding each interview into themes in this study led to the emergence of statements, as presented in appendix 5. So, for example, the code in GE's interview of 'Lack of confidence in the school', identified in participant's comments such as, 'I don't think [the teacher is] very good, to be honest' and 'I don't think they understand' lead to the stated theme: 'GE has a lack of confidence in the school to either understand or support Adpar.' Once these statements were validated by the participant (see 5.6.3), they were subjected to cross-case consideration. Considerable overlap in content and opinion in the various interviews became apparent, and the researcher became interested to find out both whether participants who had indicated similar concepts would agree with a consistent statement on a subject, and also whether those who had not mentioned an opinion on a subject would, in fact, agree on it if prompted.

### **Creation of the Questionnaire**

The questionnaire was created after the contents of the semi-structured interviews had been recorded (coded) and sorted thematically. Statements, sentiments or opinions were then cross-referenced to see to what extent a similar comment or opinion was indicated in another interview. Where these occurred in two or more of the interviews, these were recorded (see under):

| Comment:  | CY | TE | GE | SS | DN |
|---|----|----|----|----|----|
| Need for 'down time'  | x  | x  |    |    | x  |
| Child feigning illness or actually becoming ill to avoid school | x  |    |    |    | x  |
| Closer bonds, parent/child                                      | x  | x  |    | x  |    |
| Self-knowledge in child   | x  | x  |    |    | x  |
| All children with autism are different                          | x  |    | x  | x  | x  |
| School to home strategies shared                                |    |    | x  | x  |    |
| Communication/continuity between home and school shared         |    | x  |    | x  | x  |
| Child does better at school                                     | x  |    | x  | x  |    |
| Lack of specialised knowledge in schools                        |    |    | x  | x  | x  |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| Expertise shared, both home/school and school/home              | x |   | x | x |   |
| Parents become expert in their child's needs                    | x |   | x | x | x |
| Responsibility rests with the parents                           |   |   | x | x | x |
| Shared education meets the child's more specific needs          | x | x | x |   |   |
| Schools do not have the resources to meet needs                 |   |   | x | x | x |
| Learning in school is not functional for autistic child         | x |   | x | x | x |
| Parents see a 'bigger picture'                                  | x | x | x | x | x |
| Child can follow interests/develop his own strategies           | x |   | x |   |   |
| Child too exhausted to accept autism-specific input from home   | x | x |   | x |   |
| Happier child (and happier family)                              | x | x | x | x | x |
| Parents only people who fully love/understand/accept that child | x |   | x | x |   |
| Home strategies may be impractical at school                    | x |   | x | x | x |
| Schools cannot cope if child is academically able               | x |   | x |   | x |
| School is merely containing (not teaching) child                |   |   | x | x | x |
| Schools see melt-down as problem, not cause of meltdown         |   |   | x |   | x |
| Schools do not recognise stress/depression/despair in child     | x |   |   | x | x |
| School is exhausting for autistic child                         | x | x |   |   | x |
| Assessment at school not effective for autistic child           |   |   | x | x | x |
| Parents need to translate for child's communication differences | x |   | x |   | x |
| Shared education not by choice but through necessity            | x |   | X |   | x |
| Sharing education benefits child                                | x | x | x | x | x |

*Figure 5: Incidences of occurrence of themes across interviews*

Since the original comments or statements did not occur in an identical format in each interview, some rewording was needed in order to draw these together into a questionnaire. Where CY says, '[Coby] does need so much down time', and TE says, '[Elliot] needs a lot of down time', the researcher reworded these statements as 'Children with autism need more “down-time”'. However, DN does not use the phrase “down-time”, although she does seem to indicate a similar need, 'He would say, “I’m tired”.' The statement therefore reads: 'The child with autism needs more 'down time' than the typical school day gives', with an invitation to 'Agree', 'Disagree' or to indicate 'Unsure'. This allowed for DN to clarify if the phrase described what she was indicating. SS, on

the other hand, gave no indication of the concept in her interview and the statement. She indicated agreement with the statement, but she was able also to add the modifying statement, 'The downtime may need some support where children are unable to self-occupy.'

In this way, the questionnaire allowed a cross-referencing of the content of the five interviews. It allowed for checking for consistency as the researcher was able to check that participants who had indicated a sentiment in their interview, agreed with it when presented with it in the questionnaire. It also allowed for confirmation that the researcher had correctly interpreted these sentiments expressed in the interview. It gave an opportunity for participants to develop what they had said, and allowed for probing for consensus between participants. Finally, it allowed for input from 'others', outside the primary participants, to express an opinion without allowing for too much new input which might have allowed the original data to become too dissipated. An example of the questionnaire can be found at appendix 6.

#### **5.4 ANALYSIS OF THE QUESTIONNAIRE**

Responses from the questionnaire were cross-referenced to test for consistency between what the researcher had taken participants to mean in the interview and what they agreed in response to the statements. This further validated both that the researcher had understood what the original instigating participant had meant, and that the participant agreed with the sentiment on reflection (and away from the pressure felt in the environment of the interview). The responses were further cross-referenced for agreement or disagreement with the opinions expressed by other participants and not indicated initially by themselves to check for cross-case consistency.



The responses from the four participants who responded to the questionnaire show overwhelming consistency between what the researcher had taken participants to mean in the interview and what they agreed in response to the statements. There was inconsistency in only one instance: the researcher had taken DN to indicate in the interview that she felt that parents were not sharing the education of their child with autism through choice, but because their child was indicating that it was necessary. However, in response to the statement on this (number 29) DN indicated that she disagreed. Her comment on this is ambiguous:

I have always found it really important to share and have introduced Home-school books on several occasions, with limited success since teachers are always telling me they don't have time to do this and what if they have to start doing write-ups for 30 children. Usually I'm looked at as if I come from a different universe and I'm being polite. The only way it did work, was when my son had a PTA. But even then, it becomes tiring from both sides because so much needs to be reported for it to have any value or make any sense.

It is not clear, in this, precisely why she is indicating that shared education is not by choice. One explanation for the discrepancy may be the term 'shared education'. In this research study, it is used throughout to mean the child's full-time education, which is shared between home and school as two separate but interlinked elements (as in the term 'flexi-schooling'). In this comment, DN seems to be using it instead to indicate communication between home and school.

Apart from this one instance, all occasions where the researcher identified an indication in the interview which was then translated to a concrete statement on the questionnaire, the original instigating participant agrees with the sentiment.

Participants do not always agree with sentiments expressed by other participants and not indicated initially by themselves. SS is unsure whether 'The child may feign

illness and/or actually become ill to avoid longer times at school', and both she and CY disagree that "Responsibility for a child with autism's special educational needs rests with the parents." DN disagrees that 'Parents may be the only people who love/understand a child with autism; that acceptance may be essential for the child's self-esteem' and TE is unsure whether 'Parents are not sharing education through choice but because their child with autism is indicating (either verbally or through behaviour) that it is necessary.'

The responses give a total of 23 statements with which all the participants in this study agree. The path to the emergence and validation of these statements can be seen in the sample below.

**'The child with autism needs more 'down time' than the typical school day gives'**

CY: Transcript: "[Coby] does need so much down time."

"[His home-educated day] really is that break; it just is that break he needs."

Statement: [Agree] Comment: "Sensory overload in the busy school environment is a common problem."

TE: Transcript: "[Elliot] was saying that the week was too long and too much."

"[Elliot] needs a lot of down time and time alone to cope with the demands of school ... mentally he felt such a relief that there were never more than two days in a row without a day off."

Statement: [Agree] Comment: "Strongly agree – essential for functioning and learning."

SS: Statement: [Agree] Comment: "But the downtime may need some support where children are unable to self-occupy."

DN: Transcript: "Ben can't – everything comes in. So he hears what everybody says, he hears what they're saying in the next classroom, he hears what they're

saying across the hall and somehow he has to do this one thing for five minutes and talk to other people and, frankly, it's quite impossible.”

“Every time he came home, even only from one hour, he'd need two, three days to recover from that one hour.”

Statement: [Agree] Comment: “My son needs a lot more down time than other children to function within appropriate parameters”

LL (Tutor): Transcript: “He really benefits from down time and we always have ... somewhere between ten and fifteen minutes right in the middle of the morning, and he does come back renewed from it.”

EE (Edward and Eloise's Keyworker): [Agree] Comment: Statement: “Children with autism also need reinforcement as well as 'down time'.

**‘The child may feign illness and/or actually become ill to avoid longer times at school’**

CY: Transcript: “[Coby] was having just a massive amount of time off. He was probably having at least one or two days a week ...he'd feign illness, but it would look so real – because he didn't want to go in.

TE: Statement: [Agree] Comment: “I have experience of both of these [Elliot feigning illness and becoming ill].”

SS: Statement: [Unsure] Comment: none made

DN: Transcript: “After about three weeks of full-time schooling he was – you were kind of broken a bit, weren't you mate? He came home at the end of October I think and stayed home for quite a long time. He'd lost 10kgs in four months.”

Statement: “He becomes really ill. He lost over 10kg in three months and stopped growing, eating and sleeping.”

EE (Edward and Eloise's Keyworker): Statement: [Unsure] Comment: “All children may try this, not just those on the spectrum.”

**‘Extra time at home allows for closer emotional bonds to develop between the child with autism and parents/family’**

CY: Transcript: “I think it's a real closeness. We're usually cuddled up together, you know ... and we make lots of jokes together. I see that as a really special time because we're learning.”

“I just think that there's a closeness there that we get ... that it's just [Coby] and me, and for him that's learning.”

“He has a lot of time with [his little sister] actually, and he does play with her.”

TE: Transcript: “[Without shared education it was] “very hard to give [both sons] 1:1 time that I felt was important for them ... for conversation and reading with them and pursuing their own interests ... With both of them in the house together it was (still is sometimes!) just pandemonium!”

“[We] had more time to talk and listen to each other and share books and play computer games and follow his interests too.”

“[Influence of shared education was] positive on whole family as it meant Elliot was happier the whole week through and knew he was getting some time without his brother around too.”

SS: Transcript: “You are the one who develops that relationship with your child.”

“What [shared education] gave for us is time as a unit. And how to be as a unit, a family unit. Because otherwise, we'd only have the weekends ... I think it's given Edward and me the relationship that we wouldn't otherwise have had ... I've got a much better understanding of my son and my daughter through this process.”

These three statements, as validated above, together with a further 20, formed a narrative whole which provides a description the lived experience of shared education as experienced by the participants in this study.

Completed questionnaires were received from four of the five original participants. GE did not respond to emails nor to follow up hard-copies of the questionnaire posted to her with a stamped, self-addressed envelope enclosed. She became 'hard to reach' at this stage in data gathering and, whilst not formally withdrawing from it, took no further part in the study.

## **5.5 THE EMERGENCE OF SUPER-ORDINATE THEMES**

Drawing the various ways of interacting with the data described in this chapter together, it is possible to gather the perceptions of the parent participants as articulated in this study into super-ordinate themes (Smith, Flowers & Larkin, 2009). This allows the study to consider the gestalt to have emerged from the analytical process and to present the findings in a coherent and ordered way.

The provisional thematic areas to emerge from the initial analysis of the data were the Needs of child; Challenges of schools; Issues of communication/response by parents; and Potential benefits both at-home and at-school. The original design for this study was drawn around consideration of child-centred issues (including differences in sensory processing, differences in language understanding and usage, social exclusion and bullying and anxiety); school-centred issues (including difficulties in supporting academic progress and difficulties in providing specialist support); and auto-ethnographic reflection on the 'lived experience' on sharing the education of an autistic child between home and school. These considerations were further articulated in the nine propositions which informed the design of this study. The way that the original study design links into the propositions is identified below.

|  |  |
|--|--|
| <b>Literature review: elements of autism impacting school experience</b> | <b>Theoretical postulate, leading to nine theoretical propositions</b> |
|--|--|

**Child-centred issues:**

- Differences in sensory processing
- Differences in language understanding and usage
- Social exclusion and bullying
- Anxiety

**Experience of Autism:**

- Proposition 1: Shared education may address issues of sensory processing differences in the autistic child
- Proposition 2: Shared education may address issues of language processing differences in the autistic child
- Proposition 3: Shared education may address the challenges of social acceptance - and particularly bullying – experienced by many children with autism
- Proposition 4: Shared education may reduce the anxiety experienced by the autistic child caused by the pressure/pace of school

**School-centred issues:**

- Difficulties in supporting academic progress
- Difficulties in providing specialist support

**Curriculum Content:**

- Proposition 5: Shared education may allow the autistic child to better access the academic input of school
- Proposition 6: Shared education may increase opportunity to access specialist support not available in school

**Auto-ethnographic reflection and 'lived experience'****Parental Values:**

- Proposition 7: Shared education is respectful of the autistic difference in the child and does not support a 'normalisation' process (rejection of the child as 'is') which may occur in school
- Proposition 8: Shared education may enable a 'way in' for parents struggling to connect with their autistic

child

- Proposition 9: Shared education may increase happiness and reduce unhappiness in the child and – correspondingly – in the wider family.

*Figure 6: Study design links to propositions*

The link between the literature (and the researcher's auto-ethnographic understanding) and the propositions is overt in that the propositions can be seen to have been born from the literature and the understanding. The super-ordinate themes, on the other hand, emerge from the iterative process of analysis, a process which involves engagement with the transcripts, flexibility, reduction and expansion, the hermeneutic circle, revision, creativity and innovation (Smith, Flowers & Larkin, 2009).

The three super-ordinate themes to emerge from the data in this study are: shared education as perceived as a response to need (both of child and of parents); shared education as perceived as a response to the school experience; and shared education as perceived as a bridge between home and school. Each of these super-ordinate themes contains within it sub-themes which illustrate the perceptions of the parents in this study. The super-ordinate themes emerge through collection of sub-themes into groups, as illustrated below.

Theme One: Shared education as a response to need (both of child and of parents)

- 1.1: The concept of 'downtime'
- 1.2: Distress in the child
- 1.3: Building self-knowledge in the child
- 1.4: Parental choice
- 1.5: The need for time

Theme Two: Shared education as a response to the school experience

2.1: Problems with school

2.2: Advantages of school

Theme Three: Shared education as a bridge between home and school

3.1: Shared strategies

3.2: Shared communication

3.3: Shared success

## **5.6 VERIFICATION AND VALIDATION OF DATA**

### **1.1.1 Study validity and quality**

Yardley (2008) has produced guidelines for assessing quality and validity in qualitative research, and these can be used to assess the validity and quality of IPA studies generally, and of this study specifically (Smith, Flowers & Larkin, 2009).

#### **1. Impact and importance**

A real test of validity in a research study lies in whether it articulates something interesting, important or useful (Yardley, 2008). As a contribution to knowledge made in an under-researched field, this study gives voice to parents who are otherwise unheard, and allows them to articulate their perceptions of the important subject of the education of their autistic children.

#### **2. Sensitivity to context**

This can be demonstrated through the awareness of, and sensitivity to, the needs of the participants, both during data collection and in data analysis. The researcher in this study shares the life experiences both of having an autistic child and of sharing that child's education between home and school. As such, she is sensitive to stresses and emotions in a way which an 'outsider' researcher could not be, thus facilitating a 'making sense of how the participant is making sense of their experience' (Smith,



Flowers & Larkin, 2009, p.180). Additionally, the study has been careful to give participants a voice through the use of verbatim reporting throughout the exposition of research findings, and through repeated checking that participants agree with the interpretations of what they have said that are being made (Smith, Flowers & Larkin, 2009).

### 3. Transparency and coherence

Transparency is demonstrated in the full description of aspects such as how participants were recruited, how the interview questions were selected, the process of choosing pseudonyms and the steps used in data analysis. The coherence of the study is shown in the way that the findings are discussed with close reference to the literature, to the theoretical propositions and to the research questions.

### 4. Commitment and rigour

These are demonstrated both through the attentiveness of the researcher to the participant both in interview and in other correspondence, through the personal commitment of the researcher to enabling the participant to feel comfortable and through the close attention paid by the researcher to the participant's story. The study is rigorous in that it is careful in the selection of the sample to be studied and in the creation of the question schedule, and is committed to careful and complete analysis of the data collected. As an idiographic study, it is respectful of the individual participants as unique as well as being attentive to shared beliefs and experience

The study employs various strategies to strengthen the verification and validation of the data collected. These include piloting the semi-structured interview schedule, member checking with participants at various points in the research, the

parallel coding of an excerpt of the data by a second researcher and the creation of, and verification of, an 'agreed statement' by the participants.

#### **5.6.1 Pilot Study**

The semi-structured interview was piloted in September, 2014. The purposes of undertaking a pilot study include to refine data collection plans by considering research design and field processes, and to pilot the design of the interview (Yin, 2013). Van Teijlingen and Hundley further recommend it as a way of pre-testing a particular research instrument (2002).

The participant for the pilot of the semi-structured interview, TT, was recruited after she attended a conference at which the researcher gave a short presentation about her proposed research. Although TT's daughter 'Ellie' (a pseudonym) was at that time in full-time education, there had in the past been a number of periods when Ellie had been withdrawn from school to be home-educated for one or more days a week. Ellie at the point of participation was eleven years old and had been diagnosed with autism at age 2.

The researcher attended TT's house on 15th September, 2014, and recorded an hour's interview. TT was given information about the study prior to the interview (both verbally at the conference and in the form of the Information for Participants sheet – see Appendix 1) and had the opportunity to discuss the study with the researcher or her supervisors before taking part. She signed the consent form (Appendix 2) prior to the interview and kept a copy of both it and the information sheet for future reference.

During the interview the researcher used the semi-structured interview schedule but additionally allowed TT to follow her own line of description and allowing her

narrative to flow freely (Gray, 2013; Van Teijlingen, 2014). This pilot prompted a number of considerations:

#### Establishing protocols

Prior to the commencement of recording of the interview the researcher went through the interview process, elucidating TT's freedom to stop the process at any time and articulating what was going to happen to the data collected (transcription, inclusion in this thesis and possible publication and presentation at conferences). On reflection, it was decided that it would have been an advantage to include issues such as gaining informed consent, permission to record and issues of anonymity during the recording phase so that a record of them existed on the audio recording and in the transcript.

#### Use of pseudonyms

The researcher assured TT that all names would be taken out of the transcription of the interview. However, she did not discuss the issue of what identification would be used instead. When she came to transcribe the interview and to consider the use of pseudonyms, this raised several questions as to what identification should be used and, indeed, who should choose it. The researcher's response to these issue is discussed in 3.4.1.7 of this study.

#### *Semi-structured interview schedule*

The interview schedule asks open-ended questions in a way designed to enable the participant's narrative to emerge naturally (van Teijlingen, 2014). Prompts during the answering of these during the pilot study showed some tendency towards closed questioning; the researcher did not not always enable the participant to 'tell her story' without interruption. Prompting may enable stories of 'lived experience' (Ellis, 2004;

Etherington, 2013; van Teijlingen, 2014) to emerge, and can be used to motivate

interviewees to given additional information (van Teijlingen, 2014). For example:

TT: Year One? I had a few problems with the school. She went missing a couple of times. I did warn them that she will go walk-about ... I mean, one time she actually walked home, which was a worrying thing.

CL: When she was four?

TT: Yes. Yeah – very young...

CL: How far was that?

TT: For her, that was probably a good five-, ten-minute walk.

CL: Across roads?

TT: Yeah. Not main roads, but bad enough ...

CL: So, what did you do with school then, at that point?

TT: Well, I rang them up and said, '...Can you tell me how she is?' ... and there was a very long pause, and finally they said, 'Oh, she's away doing something at the moment'. And I say, 'well, I'd quite like to find out. I'm quite happy to wait on the phone...' and eventually they had to admit that they didn't know where she was.

Telling of stories of this kind can yield rich data as 'people by nature lead storied lives and tell stories of those lives' (Connelly & Clandinin, 1990, p. 2). However, the transcript made the researcher aware of the sometimes closed nature of her interruptions/prompts, and she made fewer, and of a more open nature, during the formal data-gathering phase of the study.

### Off-topic material

TT had a tendency to follow her own agenda and spent much of the interview time 'off topic' as far as this research interest was concerned. She gave a number of stories relating to her other children who do not have autism and with whom she has not shared education. This prompted the researcher to consider to what extent she should 'head off' such narratives. During the formal interview phase of the study she allowed such narratives to occur when to stop them risked interrupting the participant's 'flow', but turned the participant back to the interview schedule when possible. She also

considered the option not to transcribe any content was truly 'off topic' (although, in the formal data-gathering phase, off-topic content was rare and confined to interruptions and interactions with third parties).

### **5.6.2 Practicalities of data gathering**

The pilot study gave the researcher the opportunity to experience the field processes of data gathering prior to the study proper. Having decided to use the data-gathering protocol of voice recording plus transcription she needed to ensure that this process was both reliable and transparent. For the pilot study, she used both the voice recorder on her laptop computer and a battery operated digital recorder. She found, subsequently, that the recorder on the laptop was both clearer and easier to access for transcription, but continued to use the voice recorder in addition in order to ensure that the participant was fully aware of the recording process (the researcher alluded to the machine as she switched it on at the opening of the interview, and again at the end to indicate that data gathering had concluded). It also served as a 'backup' should the laptop recording fail, something which did in fact occur during one of the recordings in the main study (SS).

Aside from these issues, the researcher was happy that the semi-structured format and question content gave sufficient 'scaffolding' to enable data to be gathered, whilst still enabling sufficient freedom to allow participants to describe their thoughts and experiences. Indeed, in the full study, participants were found to be keen – even desperate – to describe their situation in response to the opening four questions, and in each case the interview flowed on from there with little additional prompting from the researcher.

### **5.6.3 Member checking**

The full transcript of each semi-structured interview was returned to participants 'as soon as possible' after the interview, for them to agree that it fairly reflected the conversation as they remembered it. This was achieved within 10 days (SS), 17 days (DN), 14 days (CY), 15 days (GE) and 15 days (TE). In none of the cases of transcription from audio file did any of the participants report any errors. In the case of TE, she registered and corrected a number of typos that had occurred when she wrote her original email exchanges. None of these made any alteration to meaning.

Additionally, a summary of the interview was returned to each participant as described (6.1).

The purpose of this summary was to provide a validity check by determining if the essence of the interview had been correctly captured (Hycner, 1985) and if it reflected 'the things that mattered to them' (Smith, Flowers & Larkin, 2009, p. 83) back to the participants.

### **5.6.4 Parallel coding**

Rigour for the 'mysterious act of data analysis' as described by Maykut and Morehouse (1994, p.193) is further brought to this study through the technique of parallel coding undertaken by a second researcher of an extract of the data. This technique is in line with the concept of the 'independent audit' recommended by Smith, Flowers and Larkin (2009) and builds on Yin's suggestion that a second researcher, coming to the same data, should be able to recognise the report made in a study as plausible or credible (Yin, 2013). In the case of this study, an initial sample from one of the interviews was interpreted and annotated by the researcher, and then a second

researcher – Gardner – working at a similar research level but in a different field (her PhD from Birkbeck, London, is in the writings of the late 18<sup>th</sup> century novelist Sarah Harriet Burney (Gardner, 1999), was invited to consider the same sample independently. The two readings of the extract were compared to identify any parts of it which neither researcher had identified as significant, which parts only one had identified as significant and which they had both identified. The comments were then transcribed beside each for comparison (see Appendix 4) and each analysis of the sample summarised to investigate whether there was any consensus of general summary.

*How were summaries similar?*

The most striking similarity was the extent to which the researchers agreed on which comments were significant. Both researchers identified very similarly, both in which comments were significant and in summarising what those comments were saying. Where they differed was in the explanations they gave for why the comments were made. This is in line with IPA philosophy that any account of the data should be a credible one, but that it may not be the only credible one (Smith, Flowers & Larkin, 2009).

Both researchers comment that the mother seems to allow the school to be undermined through what she says in front of her son and through what she allows her son to say without challenge, and that this might serve to reinforce her son's negative attitude towards school. Both comment on her diffidence and passivity, her lack of confidence and on her apparently apologetic stance towards both the school and her own input.

Both researchers suggest that her discussion of Adpar's home learning sound vague and lacks conviction and that she seems not to be able to credit her own experience and qualifications in education. Both comment that she is taking everything on herself and that she seems to be sharing Adpar's education from necessity rather than from conviction.

*How are summaries dissimilar?*

The biggest difference in the summaries is in the rationale given for the mother's lack of response to her son's comments. Gardner sees the mother accepting her son's behaviour without question or challenge as her allowing her son to voice what she felt passively, as saying what she would like to say but feeling she could not. Gardner describes the mother as taking the lead from the child, and as seeing the son's views as coming first.

This study's researcher, Lawrence, on the other hand, sees the mother's response (or lack of it) as stemming from a conscious Behavioural Management strategy, possibly one recommended by one of the health professionals involved in the case. She recognises that the mother uses this strategy consistently throughout the sample, and that ignoring remarks later extends to a non-confrontational approach to Adpar's refusal to act when requested. She acknowledges that this strategy may also have grown from an element of self-protection, recognising that GE articulates how much the comments would distress her if she did not use the strategy.

Gardner suggests that GE's diffident responses may signal passive aggressive behaviour, and notes her apparent unwillingness to engage with professionals. In Lawrence's case, while she acknowledges similarly that there is evidence of lack of



agreement between GE and professionals, identifies that there is evidence in the sample that GE has engaged with these. She attributes more of the responses to GE's understanding of autism than Gardner does, possibly mirroring her own levels of autism awareness.

### **5.6.5 Creation of the 'Agreed Statement'**

A more 'holistic' member check was provided by the creation of, and verification of, a statement on shared education able to be agreed by all participants. There were 23 statements in the questionnaire with which all the participants in this study concurred. For each of these statements the researcher considered the original comment made on the subject in the interview, and considered how these statements could begin to form a narrative whole. She used her 'holistic sense' (Groenewald, 2004) of the interviews and her repeated visiting and revisiting of the data, to cluster these statements together to form themes (see appendix 7). These allowed her to consider and to present a narrative description of the congruity of the lived experience of shared education as experienced by the participants in this study, presented as an Agreed Statement.

#### ***5.6.5.1 Agreed statement***

The agreed statement reads:

All children with autism present differently. What is manageable by other children may not be so for the child with autism, who may find the experience of school exhausting. The autistic child may not show stress in a typical way, and his or her behaviour may be misinterpreted by school staff who may, for example, see an autistic melt-down as the problem rather than understanding the problems which led to that melt-down. Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs, nor are schools set up to support an academically able child with autism who may still have considerable hidden difficulties, which may or may not present as challenging behaviour.

As children with autism may lack the communication skills to indicate distress or lack of understanding, parents should be fully involved in order to 'translate' for them. Parents frequently become expert in their children's autism needs and this expertise should be recognised and used by schools. Parents are frustrated if they feel that school is merely containing their child and that he or she is not learning, especially when they may have developed strategies that they know work for their child.

However, these strategies may be impractical to translate into school and it can be difficult for parents to find time to provide additional autism support at home if the child is in school all day and comes home exhausted. Schools may not have the resources for the specific therapies that children with autism need and these can be provided at home and the time tailored to meet the individual needs of the child. This may include much-needed 'down time', time for the child to follow his own interests and to develop his own coping strategies and self-knowledge. It may also allow for closer emotional bonds to develop between the child with autism and his parents and family.

The extra time spent at home can enable the child to do better at school, both behaviourally and academically. Types of assessment at school may not fairly reflect the understanding of the child with autism. Time at home allows for the sharing of expertise on the child, both from home to school and from school to home. Learning can be made functional for the child with autism's needs. Above all, shared education can lead to a happier child, which has a positive effect on the whole family. It is provision which can benefit the child with autism, and should therefore be considered as an option should parents wish to pursue it.

#### **5.6.6 Verification of Agreed Statement**

Verification that the Agreed Statement fairly reflected the views of each participant was sought by sending a copy to each. Confirmation that it fairly reflected their views was received from the participants, on 3/8/16 (CY), 2/8/16 (TE), 9/8/16 (SS) and 17/8/16 (DN). Comments received further verified agreement, including, “Document is spot on” (TE); “sounds great” (DN); “I would say the shared agreement

statement does reflect my views” (SS) and “I wholehearted agree with the Shared Education: Agreed Statement and feel it represent my feelings and beliefs in this regard perfectly” (CY).

## **5.7 CHAPTER SUMMARY**

This chapter has described the approaches to data analysis used in this study. It has described the researcher’s transparent articulation of how her pre-structural knowledge, as articulated in the nine theoretical propositions, might impact her data analysis. It has articulated how the ‘flexible guidelines’ (Smith and Osborn, 2007, p. 11) have been used in this case to engage with the rich data of the semi-structured interviews, to gather these data into clusters and into emergent themes. It has explored how these emergent themes informed the creation of the questionnaire, and how the data gathered through this questionnaire was itself analysed and coded. It has described the processes used to verify the data collected at each step in the study, and the ways that the researcher has used various occasions of member checking, together with dual coding, to validate the analysis of this data. Piloting of the semi-structured interview instrument has also been described.

## 6 CHAPTER SIX: PRESENTATION OF FINDINGS

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This chapter presents the diversity and congruity of the lived experiences of the participants in this study. It presents these findings as idiographic cases, each unique and individual to itself. It also presents the findings as examined through the ‘lens’ of the research propositions which informed the design of this study, and further presents the findings under the three ‘super-ordinate themes’ which emerged in the coding of the data from interview and questionnaire.

### 6.1 IDIOGRAPHIC REPORT OF CASES

Analysis in IPA both retains a focus on the individuality of participants’ experiences and examines where individual experiences have commonality with those of other participants (Reid, Flowers and Larkin, 2005). As such, each participants’ own story is told in this study first before cross-case synthesis is attempted.

#### **CY and Coby**

*CY's son Coby, 10, was diagnosed with autism at age 7. He attends a mainstream primary school for four days a week. On Wednesdays, he is educated at home. This home-based education includes a two-hour input from LL, a qualified teacher appointed by the family, and the remainder of the time is spent in informal education with his mother.*

CY reports Coby's initial experience of school to be 'a nightmare'. He frequently feigned illness, or actually became ill, in order to avoid school. He has always been frightened by ‘things that other children seem fine with’, and used to come out of school exhausted. In school, he would ‘zone out’; he was producing little work and would cry at night times. He would refuse to go into school, becoming very upset, and was having

a great deal of time off. His relationship with his family was degenerating as, after a day spent at school, he would not want to see his parents or his sister and would choose rather to be alone. After the school used physical force to impel Coby into school, his parents considered withdrawing him from school totally. CY sees the sharing of Coby's education through the one day at home as being a way of keeping Coby in mainstream school.

Although CY knows that Coby would prefer to be totally home-educated she feels this is not a viable option for the family at the moment and additionally feels that some school-based education is valuable for him. She feels that Coby would manage better if he could be educated at home for two days and at school for three, but she feels that she has had to argue hard to achieve the one day, something which she feels the school is still quite reluctant about, and that she has 'pushed them as far as they will go on this'.

CY feels that the introduction of education shared between home and school has had the effect of increasing the school's understanding of Coby's needs, not least through the input of his tutor LL, who is a quantified teacher and who works very closely with the school on Coby's academic learning. CY also feels that shared education has brought Coby closer to her and restored some of her son's trust in her. She says that they 'make lots of jokes together' and reports Coby to be loving and compassionate. She says that he now spends a lot of time with his sister, playing with her and taking responsibility as her big brother. CY reports that Coby is now 'a lot happier.'

## **DN and Ben**

*DN's son Ben, 12, was diagnosed with autism at age 4. He attends a mainstream secondary school with an autism unit attached for one hour, twice a week. The rest of the time he is home-educated by his mother.*

DN reports that Ben was initially diagnosed in Belgium and the diagnosis confirmed when the family moved to the UK. Ben went to school full-time in the UK for Year 3 with a full-time 1:1 support assistant.

In Year 4 this support was removed and by Christmas Ben became ill with pneumonia and did not return to school for six months. The Year 3 with the full 1:1 support has been the only year Ben has managed full-time school, and the only year he has not been off school due to illness.

In Years 5 and 6 Ben attended school for three mornings a week with his 1:1 support assistant. This TA became ill during Year 6 and Ben was assigned a number of different assistants to work with him, which he found extremely difficult.

Ben has an uneven learning profile, where he is advanced in some matters and is behind in others. He also has extreme sensory sensitivity, particularly around smells and with hearing and struggles with orientation and with facial recognition. He became extremely anxious as he approached the move to secondary level.

Ben started secondary school this year at a mainstream school with a specialist autism unit attached. The school required Ben to attend full-time. The family was not informed that Ben would have access to the specialist ASD unit until the July before he moved schools.

Ben 'crashed' six weeks into secondary school, reportedly losing 10 kilos over the course of four months and sleeping up to eighteen hours a day. He 'wasn't talking to anybody' and became 'very, very short and very aggressive' towards his sister. Ultimately, he lost his ability to do things, 'like dressing himself, going to the loo, washing himself, cutting his food, eating without choking...'

Ben at the time of data gathering [February 2016] is in Year 7. He attends the autism unit at the school on Monday mornings for one hour to have Speech and Language therapy, and on Friday afternoons for one hour to have Occupational Therapy. He has tried going into the classroom for one hour a week but found this too difficult. He is currently very wary of the school environment and is reluctant to engage with activities suggested by school. He also finds that the time he does spend in school exhausts him.

For the remainder of the school week Ben is educated at home by DN. She reports that he is starting to grow again and is putting on some weight, and that he talks more. He goes to XXX University once a month to the Computer Coding Academy and has recently built his own computer. He also completes on-line university courses. DN is exploring the possibility of his attending courses at the FE college with a 'buddy'.

### **GE and Adpar**

*GE's son Adpar, 7, was diagnosed with autism at age 6 and also has diagnoses of ADHD, Social Anxiety Disorder and 'possible PDA'. He attends a mainstream primary school for an hour and a half each day. The rest of the time he is home-educated by his mother, GE.*

GE reports that Adpar found it difficult to conform when he was at Nursery, and when he moved to school received several fixed term exclusions after he lashed out, both physically and verbally, at other children and staff. When he is in school now for his hour and a half sessions each day he spends the time 'in a room on his own with his 1:1 and is managed from there.' GE does not believe that Adpar is learning very much during this time at school.

GE feels that she accepts Adpar as he is, and, although she does understand why Adpar's behaviour is challenging for the school, she feels that staff are unwilling to listen to her suggestions on ways to manage Adpar's behaviour. She explains that 'Adpar will say things ... I explained to his 1:1, [that] he will come out with things ... and then she cried when he said he was going to gouge her eyes out with a pencil.'

Although GE would prefer it if Adpar could attend school full-time, this could only be if she believed that Adpar was actually learning during his time there. At the moment, she sees little gain in Adpar's time in school:

'I mean, when your child's at school, you're expecting them to learn something, you expect them to socialise with other children, and learn and do things but he doesn't seem to do anything different to if he was just playing at home so, you know? I can do that and not be having to keep running up the road every ten minutes to see if he's okay.'

The sharing of Adpar's education between home and school is at the school's request, rather than because it is provision preferred by GE. The school has been unable to accommodate Adpar for more than an hour and a half a day, and even within this short time makes frequent requests for GE to collect him. The school's reliance on her to share Adpar's education is causing tremendous strain, not least because GE's husband is bed-bound and she is his carer.



GE describes the current hour and a half per day provision as being '[the school's] idea in the first place ... because it's kind of preventing him from being out of school all the time, you know, being permanently excluded.' The NAS describes these practices as unlawful (2011), but confirms that they continue despite Government guidance. The illegality of this practice is confirmed in the Children's Commissioner's report, 'Always Someone Else's Problem' (Atkinson, 2013).

However, although it is not at her instigation, GE feels that sharing Adpar's education means that Adpar is happier. His behaviour provokes less reaction at home, and he is in an environment that is familiar with – and accepting of – his autism. GE believes that he is learning at home, saying that he is 'like a sponge ... he reads a book and he knows everything in that book.' She is using the extra time with Adpar to try to build strategies that she hopes might work into the future, such as accessing some Cognitive Behaviour support to help him to manage his anxiety. GE hopes that Adpar will be able to attend school full-time when he is older.

### **TE and Elliot**

*TE's son Elliot, 14, was diagnosed with autism at the age of 4. He attended a small private 'alternative' school for four days a week, and on Wednesdays was home-educated by his mother TE.*

TE reports that Elliot initially attended a small village primary school where he was 'academically ... very behind and [struggled] socially especially with unstructured time at play/lunch', but otherwise managed well. When he moved up to secondary school, though, it was 'apparent that more support was needed.' Elliot was struggling to keep up, becoming distressed about homework, and repeatedly complaining of stomach

aches. TE reports that the school was calling her 'to collect him at lunchtime with him feeling ill, it was just anxiety and unhappiness.' She recalls an incident where Elliot got 'lost' in the transition between two lessons and 'ended up alone in the library upset and unable to get where he needed to be.'

TE took him out of that school after half a term, sending him instead to a school that was 'quite alternative, for children with learning difficulties – and run out of a village hall.' Initially Elliot attended this full-time, but then dropped to four days with one day educated at home. TE was already aware of shared education as she had been doing this for the previous two years with her younger son who also has special educational needs (he does not have autism). She says that it was only possible to share Elliot's education once Arthur was settled (full-time) into his new special school, as 'having them both at home together would not have worked.'

The alternative school which shared Elliot's education was officially primary, but allowed Elliot to attend throughout Years 7 and 8. They were very supportive of the concept of shared education, used a 'very child-centre' approach and communicated well with TE throughout. They did not feel able to continue to teach Elliot after Year 8, however, even using a shared system so Elliot moved (full-time) to a school with a Specific Learning Difficulties (SpLD) unit and 'an incredible amount of support and pastoral care' at the beginning of the academic year in which data was gathered. Although he should be in Year 9, this school has allowed him to join their Year 8 cohort instead and, at the time of interview, TE reports that, at about six weeks in, this is going 'surprisingly well.'

## **SS and Edward/Eloise**

*SS's son Edward, 7, was diagnosed with autism at age 2. He is currently non-verbal. He attends a non-autism specific special school in the mornings at an autism centre founded by his mother, in the afternoons. Previously he attended his local mainstream primary school in the mornings and was educated at home by his mother, together with a 1:1 TA who also supported him in school, in the afternoons.*

*Edward's sister Eloise, 5, and was diagnosed with autism at age 2. She has some speech but her expressive language is not secure. She attends her local mainstream primary school in the mornings and autism centre founded by her mother in the afternoons. Previously she attended mainstream nursery in the mornings and was educated at home in the afternoons. [NB: Due to time constraints during the interview, the majority of the data collected is about Edward or about the children together, rather than specifically about Eloise.]*

SS chose that Edward attend mainstream nursery and Years R and 1, rather than SEN provision, as she was keen for him to maintain his access to a social environment within his community and to peer modelling. Edward was happy at mainstream and had 1:1 support, but the gap between Edward and his neuro-typical peers became more acute, and SS became concerned that the lack of specialised understanding by the teaching staff was not supporting his progress. SS was aware that Edward's needs differed fundamentally from those of his non-autistic peers and that it was difficult to incorporate meeting these needs a mainstream setting. She began sharing Edward's education by educating him at home in the afternoons, with support and input from his 1:1 teaching assistant.

The school was initially cautious about the concept of shared education, but SS and the head-teacher were able to work together to agree targets, helped by the fact that Edward's 1:1 TA was able to work across both the home and school setting.

Edward attended school in the mornings, supported by his TA, and was educated off-site by SS in the afternoons, again supported by the TA. The afternoons involved a 'very modern version of ABA [Applied Behaviour Analysis]' which was supported by consultants who oversaw it. SS was always keen that this was functional and that it would support Edward both socially and in terms of independence skills. She feels this would not have been possible in a school setting, and was easier and more effective in a 'real world' setting. The support of both the ABA consultants and the TA allowed SS to learn strategies necessary to manage Edward, and to learn to scaffold responses to behavioural issues. It also enabled her to manage Edward and Eloise together, and to spend time with each of the children individually. It enabled Edward and Eloise to spend time together to build a relationship which would have been more difficult if one or both were in full-time school, and for SS's parents, who have moved to live next door and are very much part of the family unit, to strengthen their relationship with, and understanding of, the children.

When Edward started Year 2 he moved to the local special school, still just for mornings and still supported by his 1:1 assistant. This school is not autism specific and is for what SS describes as a 'very broad base' of needs. Although she accepts that in mainstream, Edward's peer group 'wasn't really a peer group. As the years went by, the gap grew', she is not very happy with the provision offered by the special school and is considering other options. SS has founded an independent autism centre to formalise the out of school learning environment and to bring together some of the expertise she

has collected around Edward's autism education into one place. Within the next two years she hopes to open a Free School for children with autism and SLD/MLD [Severe Learning Difficulties/Moderate Learning Difficulties] as there is currently no autism-specific provision available in her area. This school will, she says, be very open to shared education.

## **6.2 ARTICULATION OF THE FINDINGS THROUGH THE 'LENS' OF THE THEORETICAL PROPOSITIONS**

As already discussed (3.2), the researcher brings to this study tacit, pre-structural knowledge as an insider researcher. She has shared the position of the participants both as the mother of an autistic child, and as a parent who has shared her child's education between home and school. As such she holds the position of a complete-member researcher, bringing a wealth of shared understanding to the analysis of the data gathered.

However, this position is not without tension, specifically within the chosen research framework of interpretative phenomenological analysis. IPA is an inductive approach which aims to capture and explore the meanings made of an experience by the participant, without prior assumptions being brought to this analytical process. As such, the researcher has articulated her prior knowledge and understanding in her theoretical postulate and through the nine theoretical propositions described in 3.3.1.

These propositions helped to 'direct attention to something that should be examined within the scope of the study' (Yin, 2013, p.30) in the design stage, and provide a useful 'lens' through which to present one facet of the wealth of data collected. This facet is presented separately from the main body of findings as the propositions reflect the researcher's auto-ethnographic, pre-structural (Tuohy et al., 2013) understanding of the concept of shared education. This separate presentation enables

the researcher to be clear about the way that her tacit understanding may have shaped her analysis of data; her 'non-neutral' stance is intrinsic to the meaning-making of the data in this complete-member ethnography study (Pietkiewicz and Smith, 2014, p. 7) as her perspective, as articulated in the propositions, cannot be removed from that meaning-making. In this way, separate articulation of the findings from the data through the lens of the nine propositions allows the data to be considered with reference to the researcher's pre-structural knowledge, and therefore for the researcher's subjective and reflective analysis of the data into themes to be transparent.

***6.2.1.1 Proposition One: Shared education may address issues of sensory processing differences in the autistic child***

The parents in this study describe sensory issues in their children as being core to their difficulties at school. DN reports that Ben's 'sensory problems are through the roof' and TE confirms that Elliot has had to learn strategies to cope 'when the noise is too much.' There are elements of hypo-sensitivity evident in GE's description of Adpar's attitude to water when she reports that 'he can't actually swim but would jump in', an experience mirrored in the researcher's experience with her son, who was banned from the swimming pool at age four for similar behaviour and at the request of the Lifeguard. Also likely to have a sensory element is Adpar's dislike of wearing clothing. GE reports, 'He doesn't like getting dressed, he doesn't like wearing clothes. It's a privilege today because he's managed to get some clothes on.' SS reports on Edward's hypo-sensitivity in the degree of sensory stimulation that he needs to "get going"; 'Edward needs water bombs throwing, eggs smashed, paint everywhere...' As she understands, such sensory stimulation is not appropriate for all children, making it a challenge to produce in school and one element of what she has tried to "add in" to his at home element of education.

Report from the children enabled by their parents in this study reflects something of their sensory difficulties with school. Coby's expression that 'school just breaks my ears' indicates a reaction to the audible over-stimulation of the school environment, and Elliot's input confirms this position when he says that at school 'you ... have to put up with a ton of noise in your ears.'

***6.2.1.2 Proposition Two: Shared education may address language differences in the autistic child***

Participants reflect that their autistic children's struggles with language processing, and indicate their belief that this creates real issues. TE recalls an incident in a Design Technology lesson:

There was then an issue ... where a teacher ... laid into Elliot for using the wrong saw. Elliot struggles with language processing and heard the teacher mention this saw so went straight to get it. The teacher had obviously been saying to them they could use any saw BUT that one.

LL, Coby's tutor, reports that 'some of [Coby's] biggest ideas and interesting thoughts come through the chance to talk and do rather than listen and write.'

Difficulties with writing, still a major barrier to the researcher's son at age 18 and just about to begin university, are reported by the parents in this study as a barrier for both Coby and Ben. Both parents indicate awareness that this can be largely overcome at school through use of a lap-top computer, although schools will still need to be alerted to the challenges for their child of, for example, worksheets or the labelling of diagrams. TE reports verbal language expression difficulties interfering with success at school she describes how Elliot was 'unable to get from one lesson to another and [was] not able to ask for help.' SS reports that Edward currently uses no spoken language and 'Eloise is verbal, but her expressive language is very, very poor.' Adpar's expressive language is reported by his mother as causing a great deal of disruption to his learning, as it is

deemed to be inappropriate in content (he interjected that various people were “idiots” fourteen times during the course of the hour-long interview with his mother, twice expressed the wish that school staff would die, once that the researcher would die and, by GE's report, regularly tells her to kill herself).

***6.2.1.3 Proposition Three: Shared education may address challenges of social acceptance - and particularly bullying – experienced by the children***

Ben reports that the other children at school are 'mean' (although does not report that they are mean to him specifically), but otherwise there is no indication that the parents in this study see bullying as being an issue for their children in school. Indeed, in line with the researcher's experience with her own son as reported (Lawrence, 2008), there are reports of positive peer interactions. CY says that 'actually his class are really very sweet with him' and SS reports that the children at his mainstream school 'wanted to look after Edward.' CY describes a self-confidence in his condition expressed by Coby, and how Coby is able to 'own' his shared education: 'As long as you go out there and you're, “OK, I'm an original but I own that” then you're fine'.

***6.2.1.4 Proposition Four: Shared education may reduce the anxiety experienced by their autistic children caused by the pressure/pace of school***

The pressure and pace of school, and relief from it, may be closely linked with the perceived need in the participants for more “down time” for their children and the assessment by a number of them that their children are “exhausted” by school. Coby's own report mirrors this when he says that his home day means that he is not 'walking across the road in a hurry to get to school on time' and Elliot similarly praises at-home days because 'you don't have to ... rush.' This element of pressure is reflected in the comments that DN makes about tests and assessments at school. She says, '[Ben is] not good with tests. He ... finds... anything that has ... to do with time restraints - out of the window.' SS reports concerns about time pressures in school, although these are more



to do with pressures which prevent the successful input of therapies that Edward needs, saying, 'He really wasn't getting a good chunk of time.'

***6.2.1.5 Proposition Five: Shared education may be a way to increase access to specialist support not available in school***

Participants in this study are keen to access specialist provision, aimed at meeting the autistic needs of their children. GE is accessing Cognitive Behaviour Therapy with Adpar to help him to manage his anxiety and his behavioural issues, and SS is very keen that Edward access autism specific specialist Speech and Language and Occupational therapies. The participants are aware that these specialist provisions are not part of the mainstream curriculum, and nor are they guaranteed as part of generic 'special school' provision. Their concerns are in line with parents responding to research by the NAS (2011) who indicated that the support which their autistic children did not get in school, but which they would like them to get, included Occupational Therapy (37%), support from mental health specialists (33%) and Speech and Language Therapy (21%). The NAS research was repeated in 2015, with indications of lack of specialist support rising in each case to Occupational Therapy (42%), support from mental health specialists (40%) and Speech and Language Therapy (25%). Additionally, parents in this study indicate the need for their children to access 'daily living' skills such as crossing roads, queuing, asking for help, time and money management, and are aware that Personal, Social and Health Education (PSHE) lessons or 'Learning for Life' lessons as presented in mainstream schools are unlikely to meet these specific needs.

***6.2.1.6 Proposition Six: Shared education may be a way to allow autistic children access to the academic input of school***

Participants in this study indicate concern that their children's academic needs are not being met at school and may be seen to be adding the at-home element in an attempt to remediate for this. GE says, 'I don't want him falling behind' and CY says of

Coby's at home time that 'he learns more in those few hours ... than he does in the whole week [at school].' CY is using (and paying for) a home tutor because she feels that she is unable to provide that education herself. 'I can teach so much, but I couldn't commit [to full-time home-education] ... It's just not something I could do.'

The issue of the at-home part of shared education being required in order to support the at-school learning is reflected in comments which CY makes about Coby's learning, 'I mean, the amount of cooking that is done here! And science through cooking, and out in the garden. Today they're building ramps.' She tells also how at-home learning can follow Coby's interests:

At the moment, he's really into dinosaurs and things and so for his last birthday everyone's like, books of dinosaurs! And kids' books of dinosaurs are amazing. We are learning so much, because it's not just learning about that animal, you've got to read about them and you can find maths to do and science, all within it – but he's just thinking we're having a nice time together messing around, so it's like 'trick learning' on a Wednesday afternoon.

Less strong to emerge in the data than in the researcher's experience is the extent to which the 'at-home' element led to active support of the 'at-school' element of education. In her son's case, the reduction of the time at school meant that he was able to access classes at school successfully. Since his overwhelming interest at the time was science (and specifically physics), this enabled him to access specific teacher expertise and scientific equipment which he would not have been able to do if either at home full-time for his education, or at school full-time but unable to tolerate the stress of this. This divergence from the research data may be in part because of the age of the participants in this study, and the fact that of the two who are of secondary school age, one has returned to school full-time and one is unable to tolerate any classroom access at this time.

***6.2.1.7 Proposition Seven: Shared education is respectful of the autistic difference in the child and as an antidote to a 'normalisation' process (rejection of the child 'as is') which parents see as occurring in school***

CY reports that force has been used to modify Coby's avoidance behaviour and to impel him into the classroom and that, even when actual force was not used, the approach of the school was still to try to persuade Coby to do what they would like, rather than responding to his communication and respecting what he expressed he needs. CY says of Coby's teacher that, 'She has managed to get Coby to go back in the dinner hall twice. The smell for him is overwhelming – the noise, the smell, so she's managed to get him to go back in there twice.' The argument for desensitisation of this kind seemed to be that the child will have to get used to various situations in order to function "in the real world." However, this does not respect the autistic child's rights, nor the fact that an adult can choose to avoid situations that he or she finds distressing, whereas a child does not have this power. DN articulates this clearly:

If you go out there and you want to do a job, obviously, you're not going to be happy with everything they're asking you to do, or they're long days ... and you need to learn how to do those things, but you're not going to choose a job that is completely nothing to do with you, you know? If you have any choice, you're not going to do that, are you? So, it doesn't make a lot of sense to me to push kids like a school does.

Despite the elements that required adaptation to be made by the children, all of the participants in this study express the wish that their children maintain some access to school, most frequently articulating this in terms of access to peer-norms. CY says that she thinks being at school may help prevent Coby from becoming 'socially ... inept' and SS is clear about the importance of social element of school for her children. She spends time during at-home time on ways to support social interaction, and then values the school time for the children to practise this. 'They [do] projects on things, so it'd be

superheroes, or Eloise would do princesses or other things that the children would talk about, so they'd have the same references.' DN is keen that the school element of shared education maintains skills such as 'where you are, and how does the school work, and what are all the rules and all that.'

***6.2.1.8 Proposition Eight: Shared education is a way in' for parents and a way to connect with their autistic child***

CY reports using Coby's 1:1 at home time to develop practical skills. '[I] teach him to wash up and put things away, like just basic life skills.' GE reports how during at home time they might be 'just standing in the kitchen and going through how you make pancakes and letting him do it and whisking the thing. We're learning how to cook and just things like that.' Elliot reinforces this in his report, saying, 'You get to go out running and do cooking and do other stuff' and DN reports how she has been able to support Ben to develop his navigation skills: 'He managed from the corner shop to here without me.' SS describes how the supported time at home gave her greater confidence to manage her children, and reporting that this extends to include the children's grandparents.

There is considerable indication in all of the narratives that the parents value the space and time with their autistic child which the shared education gives them. What does not seem clear is the extent to which they see this as 'education'. Where the researcher has come to value this 1:1 time as probably the most valuable element in the model, a view echoed by her now adult son, the participants appear to lack the confidence to view this time as educationally valid.

***6.2.1.9 Proposition Nine: Shared education is a way to increase happiness and reduce unhappiness in their child and – correspondingly – in the wider family***

The improvement in social interaction within the family is articulated by all the participants – as increased interaction between them and their child, between their child

and his siblings, between the child and the wider family and between themselves and their other children. GE describes how Adpar is 'not happy about school; he ... doesn't like it' and that 'I think he's a lot happier at home.' She justifies this opinion as being because 'I don't have so many meltdowns at home as I do if he's at school.' SS confirms that both of her children are happy at both home and school, but believes that 'had they just been school educated, they wouldn't be happy at school. It has supported the fact that they are comfortable at school.' CY articulates how sharing education between home and school has enable Coby to 'feel happier in life.' She confirms that with the provision of a day at home each week he is 'a lot happier'.

The nine propositions therefore, as well as providing a context within which to collect the data in these case studies, provide a useful starting point to the description of this data. They identify the elements of school which are seen as a problem for their children by the parents in this study, reflecting challenges for children with autism in school as recognised in the literature. The propositions also give an opportunity to understand ways that parents perceive shared education as providing positive elements for their children.

The propositions, indeed, do more than provide a starting point for data analysis; they are an articulation of the shared context experienced by researcher and researched in this study. They articulate something of the connection which exists between researcher and participant in this study, where the researcher does not just share an historic experience with the participants, but continues, throughout the study period, as a complete member of the group she is researching. This enabled the data to resonate with the researcher, and for the researcher's response to the life experiences being described to have true 'complete-member' immediacy. When TT, in the Pilot

Study, was describing how her four-year-old daughter had been lost by the school this did not just resonate with the researcher due to her son being lost by his school at a similar age, but also as current: her son – then aged 15 – had returned from a school trip some mere weeks earlier where he had become separate from the group and been lost in Belgium. The propositions, therefore, are an academic articulation of the emotional understanding of the issue of parenting an autistic child, and the challenges which entrusting that education to a school can bring.

### **6.3 SUPER-ORDINATE THEMES AND SUB-THEMES TO HAVE EMERGED FROM THE DATA**

The findings of this study are presented here, under the three super-ordinate themes which have emerged through the inductive process of data analysis, as articulated in an interpretative phenomenological analysis methodological framework.

#### **6.3.1 Theme One: Shared education is a response to need (both of child and of parents)**

Indicators for shared education being a response to need are:

- 1.1: The concept of 'Down time'
- 1.2: Distress in the child
- 1.3: Building self-knowledge in the child
- 1.4: Parental choice
- 1.5: The need for time
- 1.6: The 'Big Picture'

##### **6.3.1.1 *The concept of 'Down time'***

The concept of a need for 'down time' for the child with autism is expressed independently in the narratives of CY, TE and DN. CY gives it as the first activity which she shares with Coby during their time together, saying, '[Coby] does need so much down time' and adding later, 'autistic children need a lot of down time.' She goes on to articulate what she means by down time as being 'just ... that break he needs.' In

her agreement of the questionnaire statement, *'The child with autism needs more 'down time' than the typical school day gives'* she gives more explanation as to why she feels it is important. She indicates that she believes that 'sensory overload in the busy school environment is a common problem', although whether this is common for Coby or common, in her understanding, for children with autism is not clear. She also describes how things were when Coby attended school full-time. '[Coby] was so frightened of things that the other children seemed to be fine with. He would come out just completely exhausted.'

The exhaustion of the experience of full-time school for their children with autism is articulated by both CY and TE. CY says in her narrative that, 'When [Coby] was doing five days, you know – you're thinking, like, “O my God – I've got all of this to do and it's just ... it's just too much”' TE expresses that 'mentally [Elliot] felt such a relief that there were never more than two days in a row without a day off.' She uses the phrase 'down time' when describing Elliot's needs, saying, '[Elliot] needs a lot of down time and time alone to cope with the demands of school.' Her response to the questionnaire statement *'The child with autism needs more 'down time' than the typical school day gives'* is to “strongly agree”, adding that she believes it is 'essential for functioning and learning.' Her response to the questionnaire statement *'The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism'* is the comment, 'Absolutely. FAR more exhausting.'

DN does not use the phrase 'down time' specifically. However, she describes Ben's need for the concept in her narrative, and gives clear explanations. 'Ben ... hears what everybody says, he hears what they're saying in the next classroom, he hears what

they're saying across the hall and somehow he has to do this one thing for five minutes and talk to other people and, frankly, it's quite impossible.' She describes the effect that full-time school has on Ben, and his need for recovery time. 'Every time he came home, even only from one hour, he'd need two, three days to recover from that one hour.'

Her response to the questionnaire statement *'The child with autism needs more 'down time' than the typical school day gives'* is to agree, indicating, 'My son needs a lot more down time than other children to function within appropriate parameters.' Her response to the questionnaire statement *'The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism'* is that this 'almost goes without saying, but [it is] not really acknowledged at all.'

In contrast, SS does not give any indication in her narrative that 'down time' is a concept that she values in shared education. Indeed, more of her comments are to do with the need to stimulate Edward. Her response to the questionnaire statement *'The child with autism needs more 'down time' than the typical school day gives'* is to agree, but with the qualifier, 'The downtime may need some support where children are unable to self-occupy.' This hesitancy is supported by the response of EE (Edward's key-worker) and her comment, 'Children with autism also need reinforcement as well as 'down time'. EE 's response to the questionnaire statement *'The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism'*, is that 'behaviours may manifest at other times of the day.'

GE does not make mention of down time in her narrative.



### **6.3.1.2 Distress in the child**

In each case, it is interesting to note the reasons given for the perceived need for shared education, as these are communicated by the child. In one case (Elliot) this is reported by the parent as being a direct request: 'He was saying that the week was too long and too much'. In his own feedback, Elliot expresses how having at-home education, 'Felt like I was retired.' TE explains that 'Elliot plays being retired sometimes when demands of life all get too much ... He is very jealous of grandparents who actually are retired and have very little demand on their time'.

The children in the study tend to describe their issues with school in terms of how it is different from at-home learning, and tend to see the advantages of shared education in terms of it being 'not school'. Coby articulates something of how at-home time is less pressured, saying 'I don't have to panic to get to school', a sentiment echoed by Elliot: 'You don't have to get up and rush to go anywhere.' Similarly, Coby's issues with school are reflected in his descriptions of home. He says, 'I ... don't feel homesick when I am at home' and 'I feel more calm [during at-home learning].' Some of the descriptions of the issues with school as expressed by the children in the study are very specific: for example, 'Mrs B is very shouty'. Underlying these personal comments, though, is an impression of alienation and lack of ease. Coby describes, for example, how being at home means, 'I don't have to go to assembly', indicating his aversion to this activity. Similarly, his comment, 'Break [at home] is much better', may indicate something of the extent to which break-time at school - a time designed to be an opportunity to relax and recharge for the neuro-typical child - may present a challenge to him.

CY reports Coby's behaviour as being the trigger for her concern about him. '[Coby was] crying at night time.' She describes her concerns about his behaviour at

school and why his distress, she feels, is missed by school staff. 'When [Coby] closes off at school he becomes quiet and withdrawn but this is often mistaken as him being 'fine and calm'. TE, also, found that the school did not recognise, or at least did not report, Elliot's distress: '[School] had not really fed back at all by the time he left six weeks after he started. It was Elliot's reactions that told me he was not happy and not coping.' SS's frustration that school staff do not understand the needs of a non-verbal child with autism is clearly articulated. '[They need to consider] how was he present, you know? What was he doing? How was he sitting? Nothing – no appreciation.' She adds, in response to the questionnaire statement *'Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way'* with the comment, 'Lack of eye contact [is] interpreted as disengagement; passive defiance [is] seen as child 'not being a problem'.

There is anger expressed consistently across four of the five studies that their child's 'good behaviour' means that his needs at school are not appreciated. CY says that Coby 'would just 'zone out', he would go off into his little Coby world', and Coby's tutor LL supports this by adding, 'Quiet children that shut down can be overlooked beside the more disruptive ones.' SS's response is similar. '[Edward] wasn't running around, he wasn't hyperactive, he wasn't demanding of attention and he wasn't hitting other children. He was no trouble. You could literally just sit him down and forget he was there.' DN displays similar frustration. '[Ben] doesn't beat people up, he's not rude ... [he's been] taught in what is acceptable and what isn't acceptable behaviour. And because of that, [he's] seen as ... not having a problem.' Her response to the questionnaire statement *'Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way'* is blunt: 'Amen to that, sister!'

The fifth case study involves Adpar, whose behaviour is not compliant. In this case the parent's frustration is that the school cannot see beyond the behaviour to the child's need for education. '[School is saying], "We can't cope. Basically, can you do something with him?"' She feels that Adpar is being penalised because of his autism, which is not understood by the school. 'I did say to the school when they were saying about every child needs to learn ... and needs to be treated with respect ..., "Well, what about Adpar's right to learn and Adpar's right to respect?" and I said, "You wouldn't expect a child with one leg to run a marathon", but they didn't seem to grasp what I was getting at.'

There are various behaviours described in the studies that have led to the reduced school contact. In Adpar's case, these are ones which have led to his exclusion – either formally, or through his mother being asked to take him home. 'I was dropping him off at school, walking round and out the gate and being called back in through the other gate, you know?' His mother feels that the school reacts too quickly to Adpar's behaviour and is too quick to ask her to come into school:

They've no qualms with phoning me the minute anything goes wrong. They're not trying to sort it – they don't try to think, "Well, we'll give it a few minutes and see whether he calms down." It's like, as soon as he picks up a pencil and looks dangerous, that's it – the phone call.

The stress which this is causing is palpable.

[School is saying], "Here you are, here's your child." ... If ... I didn't have to look after [my disabled husband], I think they'd expect me to pretty much be there all the time.

GE describes what it was like when Adpar was in school more. 'I dreaded my phone ringing while he was at school.'

In other cases, the child's behaviour may be less confrontational but still indicative. CY describes how Coby would 'feign illness, but it would look so real – because he didn't want to go in.' She describes how he 'was having just a massive amount of time off.' TE agrees that Elliot has both feigned illness and been genuinely ill to avoid school, saying 'I have experience of both of these'. DN describes how Ben's illness in response to starting full-time secondary school was real and alarming. 'After about three weeks of full-time schooling he was ... kind of broken.' She explains that during this time he 'stopped growing, eating and sleeping.'

SS does not mention any school-avoidance issues with her non-verbal son, Edward, and indicates in response to the questionnaire statement, *The child may feign illness and/or actually become ill to avoid longer times at school* that she is unsure if she agrees, although she does not clarify this. Edward's key-worker, EE, also indicates that she is unsure if she agrees with the questionnaire statement, adding the point, 'All children may try this, not just those on the spectrum.'

However, SS does comment that Edward 'keeps to himself ... He gets frustrated because [communication] is another thing he can't do and he wants to be left alone', which may indicate that Edward's compliant behaviour may, at least to some extent, be used to withdraw from school demands. In response to the questionnaire statement '*Children with autism may lack the communication skills to indicate distress/lack of understanding, so parents need to be more fully involved in order to translate*' SS indicates that she agrees. DN further adds in response to this questionnaire statement, 'Even when I point out certain things ... I am told that this is not the case and they ...

aren't able to ... correct their understanding', further highlighting parental concern that communication by autistic children may be misunderstood.

#### **6.3.1.3 Building self-knowledge in the child**

Both SS and CY are clear, in different ways, on how the additional home-education time allows for development of strategies to manage their own autism by the child. In SS's case, these strategies are supported by adult intervention, but are concerned with maintaining a social 'foothold' for her son. '[Home learning might involve] having a picture of a Minion ... [so Edward] will know what a Minion is.' EE adds that additional home-education time is an opportunity to 'work on functional skills.' CY describes how during home-education time '[Coby] sees the kind of mechanics of life, of what's needed to live in a house and in a family.' He also learns how to manage his own needs, either through movement ('There's a certain amount of movement that Coby needs to do just to concentrate') or to avoid overload ('He just sometimes needs to have five minutes and that five minutes can be make or break for Coby'). DN reports that Ben is able to follow his own interests and strengths during additional at-home-education time. 'Our son loves computers and maths and spends a lot of his time just doing these two subjects.'

TE explains how the additional time at home has made Elliot 'increasingly able to self-regulate, knowing when ... he is getting frustrated or when the noise is too much.' She repeats, in response to the questionnaire statement '*Time shared between home and school allows for the development of self-knowledge in the child*' how she feels it has allowed for 'increased self-awareness and self-regulation and coping with emotions.'

Of note is that, although CY does mention following Coby's interests ('Coby suddenly like, discovers, an animal, like last week it was hammerhead sharks, and so

we'd be on the internet looking at all about hammerhead sharks'), none of the participants express that the additional home-education time is spent following their children's autistic 'Special Interests' in any major way. Rather, the emphasis seems to be on self-awareness, self-knowledge and social awareness. DN describes the importance of using that time for Ben to self-discover, 'How do I work? What does work for me? How does it work for me?' and CY articulates, 'I do think this is important for all children, to kind of know their place within the family.' DN describes how Ben is able to get some autism knowledge from the unit at school, but that 'most of that [autism knowledge] is from me.' She also says that during home-education time Ben 'learns how to keep himself safe in a situation.'

TE emphasises that Elliot's increased happiness is one of the main achievements of shared education, describing him as 'happier, less anxious, less stressed, more able to cope.' CY also asserts that what is achieved by additional home time (and diminished school time) is that Coby is happier: 'It helps him feel happier in life, so therefore, that's going to rub off.' She emphasises how important Coby's happiness is to the family dynamic. 'He's a lot happier, and if he's happier it just ricochets through the whole family.'

This wider family implication is echoed by SS, especially in her description of how additional at home time has influenced the relationship between her two autistic children. She describes how their at-home time was designed to correspond, so that 'they could do their experiences, they could learn things together' and 'gave us a sort of opportunity in a scaffolded way for them to build a relationship.'

SS believes that the wider family, too, has been affected. '[The children's grandparents] have been part of this whole journey ... they have shared things – like my

dad will go and feed the birds with Eloise. Eloise can now name most of the birds in the garden, which is joyful – just a joy.'

DN describes how her son's autism was preventing communication, and how the exhaustion brought on by full-time school exacerbates this: '[When Ben was in full-time school] I had no contact. None.'

In the one instance in the studies where support moves across the environments of home and school in a managed way, it is clear that additional out of school time can be used to develop ways to manage autism by the parents. EE, Edward and Eloise's key-worker who supports them both at home and at school, explains that at-home-education can be a 'time for parents to receive training/support/input from 1:1 tutors.' SS reinforces this, explaining that EE would be 'helping me to manage the behavioural issues ... if Edward wouldn't hold my hand, or if he would hit me or so on and so forth.' She explains the way the formal support from EE feeds into Edward's at home time:

[EE is] not there at the end of the day when I'm undressing him, getting him ready for bed, bathing and all of that stuff, and as we were saying its everything, 24/7 education for an autistic child isn't it? But for that structured time in the afternoon I very much treated it as a capsule ... He wasn't at school but we were following a programme.

She adds that, without the structured input she 'wouldn't have felt confident in dealing with Edward's response.' In this case, shared education between home and school allows the school to support the parent to meet the needs of the child.

#### **6.3.1.4 Parental choice**

There is a lack of consensus in the studies about the extent to which the decision to share their autistic child's education is a matter of choice for the parents. Only TE, of the participants, gives any indication that shared education with Elliot was a deliberate

option. She had previously shared her other son's education (he also has additional needs, although not autism):

I had loved doing it with my younger son and felt he (WE actually!) had gained a lot from it and it was Elliot's turn to have some one-to-one and partly because he was saying that the week was too long and too much.

TE indicates that in many ways her moment of 'choice' came earlier, when they discovered the small village hall special school with whom they shared Elliot's education. Moving him to this school reduced Elliot's stress and provided a platform from where they could share his education. Before this, in mainstream secondary, 'he was not happy and not coping. When we found an alternative, we were straight out.' She indicates on the questionnaire that she is unsure how much the decision to share education can be seen as a choice for all parents. 'Some parents are choosing. Some may prefer not to share but need to.'

This feeling that sharing education is something parents feel is imposed upon them is echoed by CY. She says in her narrative, 'It's the only way. It's the difference between being in school and not being in school I think.' SS similarly indicates that taking an active role in her son's education is something that she felt she had to do: '[School] really didn't know what to do and didn't have the resources to support Edward. And that's when I decided, actually, that I'd take him out.' DN is amused by the suggestion that other parents might choose to share education as a life-style choice rather than by necessity. 'You know, really? Who wants this? No-body wants this!' She suggests that she has to be involved in her child's education as she is the only one who seems to understand his needs, with an understanding built on a lifetime spent with Ben:



Experience has taught [me] that there is a way that might work and there are ways that certainty don't work and, if they haven't changed in seven or eight years, they're not going to change, are they?

CY comments, similarly, 'I'm the only one who totally gets it' and EE regrets that parental expertise is seldom recognised by professionals, 'It's a shame [parents'] opinions aren't always accepted/valued.'

In response to the questionnaire statement, '*Parents often become expert in their children's autism needs and this expertise should be recognised*' CY responds, 'Absolutely!' and TE, 'Absolutely, yes, yes, yes!' SS recounts how difficult it was to be heard as a parent, even at the diagnosis stage:

SS: The paediatrician told me that Edward was not autistic, but he just wasn't being stimulated ...

CL: *So, that it was your fault?*

SS: Yers! It didn't make me feel very good about myself ... [but] I persisted. I persisted."

DN suggests that she has no choice but to share her son's education at home since his going into school full-time is just not viable:

In our case, [full-time school is] impossible since it results in anxiety attacks, not being able to eat, sleep or have a bath, due to sensory overload. So, full-time education ... [would mean] that we cannot provide elementary care anymore. Full time education, therefore, is not an option.

For GE, too, sharing education is not a choice. Adpar is at home for some of his education at the request of the school, and she feels that even when he is in school, he is not learning:

If they did what I'd expect a school to do with a child, then ... I wouldn't [share education] but, because of how they are, I feel I need to do that because, otherwise, I don't think he's going to learn anything.

GE does her best to meet Adpar's learning needs out of a feeling that if she does not do so, he will not receive an education. 'It's just me doing it because I don't want him to not have a job when he comes to work, you know?'

#### **6.3.1.5 *The need for time***

Strong across the cases is that what parents get from sharing education with their autistic child is additional time. TE says that '[with full-time school it was] very hard to give ... the one to one time that I felt was important.' and CY says that Coby comes out of school 'completely exhausted.' DN explains in more detail:

[Ben will say] "We've learnt about this" and then we go and dive in and make it this big thing. On top of full-time schooling, that's not possible. That's not possible because, when Ben was in school more ... we were up 'til ten, eleven, twelve o'clock at night, trying to figure out what it is so [he] could actually go to bed.

For SS, the time at home is an opportunity to provide the therapy that Edward needs in a more focussed way:

There were issues about therapy at the school ... When they did try to do 1:1 stuff with him they were trying to squeeze him into corridors ... or they just could not find a room to do it in or by the time they set it up, so much of his day was being eroded by you know moving from one room to the other ... So, all of that was removed, all of that was done at home.

SS has been able to use the time that Edward is out of school to work on his communication, supported by the input of professionals:

We went to see this wonderful Speech and Language therapist ... and she said, if she had her way ... no child would go to school until they had mastered PECS [Picture Exchange Communication System]. And she advocated Edward coming out of school.

Another advantage of the additional time for the parents to spend with their autistic child is that it means that it can 'free up' after school and weekends for the rest of the family. CY comments, 'I actually have more time for my daughter, and family time because I'm not dealing with screaming and crying.' She also believes that enabling Coby to have time at home during the week makes him more able to interact with his sister when she comes in from school. 'He has a lot of time with [his little sister] actually, and he does play with her.' The effect on sibling relationships is echoed by TE who says, '[Shared education] meant Elliot was happier the whole week through and knew he was getting some time without his brother around too.' SS explains how shared education has enabled her to 'spend time with one child and then the other ... so I have a better independent relationship as well as joint relationship with my children.'

This additional time is felt by the parents in the study to facilitate the bonds between them and their autistic child. CY describes their at-home time: 'It's a real closeness. We're usually cuddled up together, you know ... I see that as a really special time.' TE expresses that more time at home with Elliot meant that they had 'more time to talk and listen to each other and share books and play computer games and follow his interests.' Elliot reinforces this, saying in his feedback that shared education means that, 'you get to see more of your family.' For SS, the additional time with her children is important for her to develop her relationship with them, and for them with her and with each other:

What [shared education] gave for us is time as a unit. And how to be as a unit, a family unit. Because otherwise, we'd only have the weekends ... I think it's given Edward and me the relationship that we wouldn't otherwise have had ... I've got a much better understanding of my son and my daughter through this process.

The parents' readiness to accept the autistic child is important to GE. She says that Adpar's autistic behaviour 'didn't really bother us. He was slightly different to his brother, you know, but until he went to school and interacted with others it - it wasn't really a problem.' TE shares this emphasis on acceptance, saying, 'Parents love/understand a child more than anyone else. This acceptance is vital.' SS believes that it essential that parents are the ones who are involved in working with their autistic children, rather than this falling to professionals in school. As she explains, it means that 'you are the one who develops that relationship with your child.'

DN values the time she spends with Ben because she feels that 'without restoring this bond [with her] on a daily basis there is no safe place for him and anxiety becomes overwhelming and debilitating.' The idea of the parent as a 'safe place' is echoed by CY: '[Coby] sees me as home, really. Like I am 'home' ... There's just so much safeness.' She is aware of the vulnerability which autism brings her child:

Children with autism can struggle to know their place in the world and the parental unconditional acceptance is therefore paramount ... You've got all these kinds of issues and then you've got that one person who totally gets it and you love completely and you just totally trust.

#### **6.3.1.6 The 'Big Picture'**

The parents in this study seem able to see their autistic children not just as they are now, but with understanding of their pasts and also, importantly, with concern for their futures. They appear to see 'education' in a far broader term than schools may be able to do. DN says:

We are not confined by the guidelines that schools have to live by and we see our children in a non-school environment therefore we know what is really needed, where schools only know what is needed within an academic setting.

For SS, her son's learning priorities as she sees them do not correspond with those of the official curriculum. 'For Edward ... being able to know all his colours isn't all that functional. For Edward, what is functional is being able to put on his trousers.'

CY believes that it is important for Coby to understand the way the world works: 'In order to have the things that we have, there's a certain amount of kind of 'stuff' that we have to do so I think his learning that is really, really important.' TE is concerned that Elliot learns about his own autism and how to meet his own needs, saying that he needs to be aware 'when his mood needs lifting or when he needs to work harder at something.'

### **6.3.2 Theme Two: Shared education is a response to the school experience**

Indicators:

2.1: Problems with school

2.2: Advantages of school

#### ***6.3.2.1 Problems with school***

In these case studies the parents are sharing education because they perceive that the school is not able to fully meet their child's needs. Central to this is their perception of a lack of understanding of autism in schools, and of a failure of the school to understand the needs of their child specifically.

TE is the most positive about the school that shared her child's education, but she explains that it 'was a school that was quite alternative, for children with learning difficulties – and run out of a village hall.' This school had already provided her with an

alternative after the mainstream state school experience 'did not go well.' At the mainstream school Elliot had been a 'miserable, distressed little boy', and the small alternative school enabled them to move to a 'very supportive' shared education:

They would let me know what they were doing and any issues with things he had struggled with so I could pick up on things if I wanted to ... This school being very small and specialist was ... working in quite a child centred way.

CY expresses frustration that Coby does not meet the perceived profile of an autistic child as understood by the school. '[With Coby] there weren't the typical signs that the school were used to.' She believes that some of the strategies that the school has used in the past have been damaging. 'We had a couple of occasions where they physically brought him in. I think that was a turning point where a lot of trust was lost.' CY has found it difficult to get her suggestions as to what will help Coby heard at school. 'I ... sort of suggested [a break], but the teacher [said], "Oh no ... If he has five minutes they'll all want five minutes. It'll be anarchy."' She is conscious that the school is not particularly positive about shared education and is worried that if she asks for any further flexibility, she risks the school withdrawing the provision of shared education:

I wouldn't dare ask ... I think I've pushed them as far as they will go on this ... [Shared education] was all so new to them. It took a lot of coaxing ... They tried to make it just a short-term thing. I had to really argue it, and they were saying maybe just one afternoon. So, a full day is just about the most I could get out of them.

GE feels the school does not have the experience to understand Adpar. 'They've dealt with children with ADHD but I don't think they've dealt with children that have got ... ASD and ADHD and possible PDA.' She feels that the school is struggling to contain Adpar's behaviour and is not actually teaching him:

Adpar doesn't go into a class; he's in a room on his own with just him and his 1:1 ... I don't think he learns an awful lot while he's there. He doesn't do any actual structured work as such.

GE feels also that the school is too quick to call on her, and finds the short length of time that the school will allow Adpar to attend demanding on her:

[Adpar attends for] an hour and a half at school ... I'm pretty much there most of the time with him ... We have this what we call 'sofa time' where, instead of staying outside in the playground with the rest of the children, we go straight in ... until the bell goes and then we move round. And then I'm there with him for a few minutes, then I come home and ... by the time I've walked home and had a cup of tea, it's time to go and pick him back up again.

DN feels that the school is not alert to the stress that Ben is under as he doesn't manifest his stress in challenging behaviour. '[He's] seen as ... not having a problem and what isn't seen is how much that behaviour takes out of the energy [he has] in a day.' She is frustrated that the provision they offer is often itself inflexible:

[In] Year Five .... they threw like nine different TAs at him ... he doesn't have facial recognition ... so he's always surrounded by ... strangers ... We asked them and said, "He needs either one TA or maybe two if there's no other way around it", but then it's like, "No, we don't work like that."

She feels 'reasonable adjustment' for children with autism is often token and inadequate, as in the example of the transition that was arranged for Ben between primary and secondary school:

Ben went three days to this school but, normally, they only go one day and that's then a 'big transition' ... I said, "Well, he needs to be there for six months only half a day and then maybe he'd be alright."

She is aware that there is a continuing pressure for Ben to attend more hours because 'attendance is [seen as] more important than personal well-being and development, especially when it comes to sensory and mental health issues.' She feels that this pressure is counter-productive:

The constant push for our son to be in school more than he's happy with is making him anxious and he does a lot worse because of it. It actually has the opposite effect, with him not wanting to learn or do well because doing well results in the punishment of having to go to school.

SS is aware that the school that Edward attended initially was 'not equipped, or not skilled, to deliver ... [as] at the end of the day it was a mainstream setting [and] they weren't specialists.' She was also concerned that the curriculum was not sufficiently flexible to meet his needs:

[Edward] needs to tolerate having his hair brushed, teeth brushed, having his feet measured; these things cannot be taught in a mainstream school. But just because a child needs to be taught that it shouldn't rob them of the opportunity for a mainstream experience.

The inability of their local community school to meet Edward's needs became more obvious as time went on. 'As [Edward] became older and the gap became larger, the lack of understanding of the teaching staff became more and more evident.' However, even when Edward moved to a special school it was not autism-specific and SS found 'there just aren't the resources in school to do 1:1 teaching.' She decided that in order for Edward to receive the input that she believes he needs, she would share in his education and provide it herself. She requested for a 1:1 support assistant with autism training be engaged to support Edward in school, and that this TA hours would



continue to provide support during Edward's at-home time, thereby providing consistency across environments.

CY, DN and GE all express concern that mainstream schools lack the specialisation to meet the needs of children with autism, but that special schools lack the provision to meet the needs of children who are academically able. DN indicates concern that mainstream schools 'don't get how a kid that is, purely in learning, so advanced as Ben has so many problems.' She knows that Ben's uneven profile causes difficulties in a mainstream setting. 'Last year, his knowledge was that of a seventeen-year-old ... but ... his ... "How I am in the world" ... is like a seven-year-old.' She feels that his at home-education will better allow him to reach his potential:

We're looking now for advanced algebra and the beginning of quantum physics ... he's just built his own computer ... and he's doing Cyber Security [with the] Open University. That is a structure that really works for him because it's just so clear and he sees where he is and what he still has to do.

GE, too, is aware of Adpar's intelligence and that this is not being nurtured at school. 'When he was two, he got up one morning and logged onto the computer and sent his uncle in Newcastle an email, you know?' She feels that society does not understand that Adpar can have such specific challenges and yet be intelligent. 'I think the problem is ... a lot of people believe that, if you're special needs, you're ... slow ... and where that's not the case ... they can't put him in a box.' CY comments that sharing education allows Coby to avoid having to go to a 'different, more specialised school that may not allow him to reach his full academic potential.'

The children are quick to express that their learning needs are met more fully at home than at school. Elliot describes how, through shared education, he 'learned a lot

more than I did in school' explaining that this was because 'it is more relaxed.' Coby says that during at-home time, 'I find it much easier to understand things', adding that LL, his tutor, 'is good at making learning fun.' When asked for specifics he describes: 'We do this thing called sweetie maths and if I do it I get to eat one of the sweeties. We use sweets to count. I like sweets.'

#### **6.3.2.2 Advantages of school**

Despite concerns about the school environment the parents in the study are all keen that schools remain involved in their children's education. CY feels that responsibility for Coby's education should not rest entirely on her, but that it 'should rest with the school also.' DN agrees that 'it's a joint responsibility' and CS indicates that responsibility 'rests with all parties involved to make sure the curriculum is properly accessible.' DN argues for the autistic pupil's right to have a school-based education that is tailored to his needs:

I ... think, personally, that every child ... has a right to an education, even if it is difficult. And it's not because we don't learn in in a certain streamlined way that we're no good at anything.

She adds that although she believes that parents may know what works best with and for their child, schools also have an important role.

Providing for a child completely on your own back [*sic*], is almost impossible and doesn't necessarily give the child the best opportunities either. Staying embedded in society is a must, and with mutual help we can make significant progress, I am sure of it.

SS is particularly positive about the advantages of the specialist support she has received working across both home and school. She, GE, DN and CY are all keen to credit examples of where support offered by schools has been positive. GE describes

how, when Adpar was in the Infants, 'he had a 1:1 who was brilliant [and who] tried her best to adapt and redirect things ... She learnt what would set him off and sort of steered the learning around that.' CY is similarly positive about Coby's current 1:1 support assistant:

She's lovely ... she has her own autistic son so she just totally gets it. It's unspoken with her – she just knows and when it all gets too much she's just straight in there, big cuddle, takes him out of there, go and do something else – she just knows.

SS reports that one of the advantages of school for Edward has been the opportunity to build 'a relationship with somebody who was outside of the family.' She remembers a particularly strong relationship from his early years at school:

He very much liked the 1:1 he had. He had the same 1:1 five mornings a week for two years and they definitely had a bond. But we did have the issue that after every holiday when we took him back it was difficult for a while but they managed to rebuild that relationship.

DN recalls the support which Ben received during the only year that he has attended school full-time, and regrets that this level of support was not maintained. It was in Year Three, when they had just arrived from Belgium with the diagnosis:

In Belgium, he was taught in Dutch (Flemish), so, he was so far ... behind that he got a complete 1:1 ... and, at the end of Year Three, he'd caught up ... And then, in Year Four, they took everything away because they said, "Look at him, look what he can do!" and they dropped him in a classroom and, within three months, he had pneumonia and didn't recover for five or six months.

Despite the many concerns about school that are raised by the participants, none wishes to withdraw their child totally, and each believes that there were advantages to their child which (some) school attendance offers. GE is the only case where part-time

school attendance is at the instigation of the school. She is clear that she would prefer Adpar to be able to attend full-time; in response to the question, '*If he could go to school full-time, would you?*' she responds, 'If they did what I'd expect a school to do with a child, then ... I wouldn't [share his education]'. She is clear about what she would like from the school. 'When your child's at school, you're expecting them to learn something, you expect them to socialise with other children, and learn and do things.' She hopes that Adpar will be able to attend school full-time in the future. 'I'd like Adpar ... by the time he goes into Secondary... to go full-time. Whether that works or not we'll have to see.'

CY is at the other extreme of the provision in that she would prefer it if Coby could spend more than just one day of his education week at home. 'I think, if we could have got two days [at home], then three days [in school], then we would have nailed it.' She is aware that Coby would prefer that he learn at home full-time ('He would do this five days a week if he could'), but feels that this is not an option for her. 'I have to work, and, I don't know... I can teach so much, but I couldn't commit ... It's just not something I could do.'

TE is also aware that her son would prefer not to attend school, saying, 'He has never been a fan of school and given the choice would actually prefer [home-education] totally I know.' She saw the time sharing his education as a way of trialling the option of educating him at home full-time should that become necessary: 'I ... wanted to test the ground for what a day of home-education might feel like.' She was aware that Elliot, now 14, had to move on from the informal specialist school he had been attending, and that continuing to share his education between home and school at secondary school was not possible. 'I work three days a week and ... so [dipping] into

the subjects he wanted to study and out for those he didn't ... would not fit around my working hours.' She was also wary of alienating the school by requesting sharing of education. 'I was so relieved that they had been flexible with other things I did not want to rock the boat.'

SS worked hard to allow Edward to attend his local school, even part-time, and is clear about the benefits which this has brought him. 'What was important for Edward from school was social exposure ... He needed ... to be ... part of the community he would grow up in.' She is confident that this has been valuable. 'Everyone knows Edward now ... he's accepted within his community for how he is and not judged.' Once he had moved to a special school for his school-based education, she was keen that continuity was maintained between his home learning and his school learning:

[We were] making sure there were no conflicts in terms of approaches or strategies ... it was just simple things, sometimes, like they'd be using their 'Choice' icon and you'd look at the 'Choice' icon and what do you know? It's different!

She achieved this continuity by arranging that Edward's 1:1 support would move across the environments of home and school. She is now co-founder of a specialist therapy unit for local children with autism, and currently Edward's education is shared between a generic special school and this unit. Edward and his sister Eloise, who is also autistic, are the only children in the case studies who are described as enjoying the time that they do have in school. SS believes that it is the additional at-home time that has made this enjoyment possible. 'I think had [Edward and Eloise] just been school educated, they wouldn't be happy at school. It has supported the fact that they are comfortable at school.'

DN's son Ben also has access to an autism-specific unit attached to his mainstream secondary school, although DN feels the unit does not provide a suitably academic environment for him. The unit is staffed by teaching assistants, and 'teaching assistants aren't teachers.' She is concerned that 'they just go over the same things over and over again and they can only do what the ... classroom teacher allows them to do.' DN is keen that Ben retains access to the social input of school as he has 'a great need to be in with other kids.' However, he also finds the social interaction of school a challenge. 'Ben is saying like, "They're all rude and they swear at each other and they're mean."' DN is keen that Ben does maintain some element of a school as it allows him to better access the education system. 'Ben wants to go to University, [and school allows him to] keep having that foothold.'

### **6.3.3 Theme Three: Shared education is a bridge between home and school**

The third theme to emerge from the data is that of shared education being a way to provide consistency across the environments of home and school. Strategies may be shared and communication enhanced. There is the possibility of a celebratory approach, where the achievements of the child, as opposed to perceived limitations, are at the centre of the provision.

Indicators:

3.1: Shared strategies

3.2: Shared communication

3.3: Shared success

#### **6.3.3.1 Shared strategies**

CY and GE each give examples of strategies that they have suggested to take into school, and SS gives examples of strategies that the school has suggested which have worked at home.

CY gives the example of the strategy of giving Coby as specific job to do, which she uses at home and which has translated successfully to school:

With the teachers who have been happy and prepared to [give him jobs], it has worked really, really well. It is a really good tool for kind of coaxing him in to doing something. It's like, with sport: he doesn't like doing PE, but he'll help get the balls out, you know? When we have kids' parties, he'd never want to be involved in Pass the Parcel, but he'll press the button on the music. So, it's involvement of sorts, which I think is really important and that's something I think I managed to convey to [school] and they've adopted.

LL, Coby's teacher has a further example of successful sharing of strategies:

His teacher ... said, "I don't know what to do when he shuts down" and I said, "I give him something different to do" ... He then put together a box of things Coby could choose from when he was having that "I can't do it" moment, which was really, really effective.

GE similarly has suggested strategies to the school, although these seem not to have been fully understood: 'Adpar will say things that you just have to ignore ... I explained this to the 1:1.'

SS makes the strongest report of strategies from school which have helped her at home. These primarily seem to be delivered by the 1:1 support assistants who work with Edward across both environments. These tutors work on 'guiding ... on how to manage [her] children.' SS reports that she, 'needed help to enable me to do that effectively ... Where there are elements ... that I have done on my own ... they do tend to be things that I've been shown first.'

She is very concerned that successful strategies that have been developed at the autism unit which she has founded are translated to the other children's home environments:

We ... do outreach here so ... [if parents want] to go bowling, for example ... we'd come up with various strategies and a member of the team will come up here see what's happening, work out what's happening, work out some strategies. We then do it and then they come out three weeks later to check how we're doing.

EE, Edward's key-worker, comments that, 'General special schools [are not good at passing on strategies] ... TreeHouse (autism special school) was much better at this.'

The response to the questionnaire statement, '*School may be able to suggest strategies that can be helpful at/translated to home*' elicited agreement from CY and the comment from TE, 'I am sure many schools can ... though I did not use school's strategies. [I] felt I knew my son best.' This feeling that the parent knows the child best is echoed by GE, 'I think I know a lot more [than the school does] about my child ... because I know what works.'

LL, Coby's tutor is also confident that she knows which strategies are successful with Coby, although she remains open to advice:

I feel, two years down the line, we've worked out what works, you know? [However,] I'm always happy to hear if they're doing something in a specific way at school, I like to hear that because then we do that way here and reinforce that.

#### **6.3.3.2 Shared communication**

The idea that sharing education between home and school facilitates communication and continuity is one that CY agrees with, although she cautions that it can only happen 'when a good line of communication between the parent and teacher is established.' SS similarly affirms that 'It's so important to have constant communication.' DN gives an example of where communication between the school and herself has allowed her to overcome a difficulty that Ben was experiencing at school:



Last year, he wasn't reading in school at all and he was so many levels behind other children until his TA said, "Can't he bring something that he's reading at home?" and he was reading Tolkien ... And [he brought the book in and] ... they did a test and he ... went up like five levels or something ... there was nothing in the library that he hadn't read that was of interest to him and he doesn't like stories.

She explains that it is important for the school to communicate with the parent of a child with autism, as the child may not be able to make that communication himself. 'My son can't explain to me what happened because he gets terribly overwhelmed by the school experience.'

LL (Coby's tutor) confirms that communication is very helpful, adding that 'the school have been very good at communicating directly with me since a working relationship was established.' She explains that this enables her to prepare ahead with Coby. 'If I see something that's coming up in two or three weeks' time that will be a new concept, I try and do it first ... because then it's not new to Coby.'

SS describes clearly in her narrative how effective it is when school and parents work together and communicate effectively. She describes how she 'worked with the school to come up with structured targets, so we could support what was going on in school and school would support what was going on at home.' EE, Edward's key-worker, cautions however that communication is only effective 'as long as the school are willing to continue with targets/goals set at home.'

#### **6.3.3.3 *Shared success***

CY is confident that Coby's day at home each week leads to greater success in school for the other four. 'He's got Wednesdays [at home] – good day – then he's pumped back up for another couple of days.' She explains that she believes that the day at home means that Coby is 'more “there” [when at school] ... more mentally there

because there's less time to deal with for him.' It is also a way of getting him into school. 'He's a little bit more willing to be there because he knows it's not his kind of epic mountain anymore.'

SS describes how the work she does with Edward out of school feeds into his experience in school. 'We ... do ... all the enrichment ... out of school, so that he [can] generalise it into school ... which [has] proved extremely successful for Edward.' EE reinforces the importance of this, 'especially as children with autism find it hard to generalise skills.' DN describes how she has tried to coach Ben in order to maximise his ability to tolerate school. 'School becomes a subject, something you train yourself to be good at and can be taught.' EE agrees with this: 'Skills can be taught intensely at home and generalised to school and group.'

SS describes how Edward's home learning is 'very much in a natural environment and it's very much out in the community' which means that he can 'generalise that knowledge into [school]'. CY also recognises the value to real life learning, and his tutor, LL, articulates why the home environment may allow the child with autism to gain confidence in his learning: 'If you're pushing someone to make new discoveries ... then they need to be in an environment that they feel safe.'

DN is aware that a part of Ben's anxiety at school is because he struggles to recognise either the people or the place, and tries to structure home learning to help build these skills: 'He doesn't recognise any faces [and] he doesn't have any orientation ... we tried to take him out, here, just go around and try to let him lead.'

She believes that the extra at home time enables there to be 'enough energy and focus left' for her to teach Ben 'how to be in the world and how to apply what [he learns] in school and test it against a society/community background'.

One of the essential objectives of the parents in this study is the wider position that their child should be happy. Although they may feel that as parents they are not, or should not, be solely responsible for their child's education, this sense of responsibility for their child's welfare comes through strongly. TE indicates, 'I would not let [Elliot] be in an environment that was not positive for him', CY is concerned that 'if we stopped [sharing education] now, it would seriously impact [Coby's] life' and SS says, 'I have worked very, very hard to make sure that both of my children are very happy.'

#### **6.4 CHAPTER SUMMARY**

The rich narratives given by the participants in response to the semi-structured interview and subsequent questionnaire have been a fertile source of data. The difficulties and frustrations which the parents feel about, and the children experience at, school are clearly articulated, as are the many potential and sometimes actual positives which they believe some school attendance can yield. The parents' belief in the many benefits provided by the home-education part of the children's school is also clear. Whilst there is significant divergence in the experiences of the participants, there remains a degree of concordance in much of their understanding of the reasons behind their experiences, and their belief in ways forward for their children. The shared education, whilst not always delivering all that participants express that they would prefer, is seen to provide potential for improved communication, for strategy sharing and for problem solving.

The findings suggest that the children's problems with school include the expected areas of sensory difficulties, language issues and anxiety. Shared education is seen by the parents as a way of reducing these stressors, and of making their child's education more individualised, providing their child with more specialised support.

Their wish for their child to continue an element of school-based education is most frequently articulated in terms of access to academic input.

Shared education is seen as a way of providing an education which is more respectful and accepting of their child 'as is'. Although there are indications that the parents in this study are refusing to accept limitations imposed by others on their child because of autism, there is no indication that they themselves are refusing to accept that autism. They all show strong and realistic autism awareness and understanding.

The parents in the study indicate that they value shared education as a way of connecting with their child and of making their child (and their whole family) generally happier. Although there is frequent indication of their child's improved social interaction with them and with wider family because of shared education, there is no indication in this study that the shared education had come about because of social difficulties such as bullying at school.

Shared education is believed by the parents in this study to give the child a break from what is seen as the unsuitable environment of school. Although it is something that has been instigated because of the parents' awareness of their child's distress, most parents indicate that they see it now as a positive opportunity for their child to understand himself and to work with, rather than having to hide or 'manage' autism.

Parents in the study are unclear to what extent they see sharing education as a 'choice'. They indicate that they are doing it because they see no alternative, yet they also value it as something that they have elected to undertake – as something fragile but worth preserving if possible. One element indicated as making it worthwhile is that it gives them time to spend 1:1 with their autistic child away from other demands, and time for their child to be with them when not exhausted by the demands of school.

The parents in this study see current provision as being firmly rooted in the life journey of their child. All alluded to the need to get education right in order to provide for their child's future.

The parents in this study are very aware of the ways that school is challenging for their child, and of what they perceive to be failures by the school to meet their children's individual needs. Each sees sharing education as a response to unsatisfactory experience by their child of school. However, each is also keen to maintain contact with school, and generally they are hopeful that school could be 'better'. Each is able to recall positives which their child had experienced at various points in their schooling.

Most parents seem to indicate that they would welcome stronger links across home/school, especially regarding the need for school to listen to them as the person who knows their child best, and (to a lesser extent) regarding support for them with the curriculum elements of their child's education. The need for good communication more generally comes across strongly, especially the need for schools to indicate to them what happens in school (provide context), so that they can help their child with issues and avoid problems.

Parents in this study indicate the need for a more positive, child-centred approach by schools, and for staff in school to accept, understand and indeed to 'like' their child as he or she is.

## 7 CHAPTER SEVEN: DISCUSSION OF FINDINGS

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In this chapter the findings of this study are discussed in comparison with similar phenomenological research studies, conducted with parents of autistic children who home-educate and with those who share education of their autistic child between home and an outreach education provision in Australia. The findings are further discussed in the context of the extent to which the themes which emerge are concordant with the extant literature and the researcher's theory development.

### 7.1 DISCUSSION OF THIS STUDY'S FINDINGS WITHIN THE CONTEXT OF SIMILAR PHENOMENOLOGICAL RESEARCH

Similar phenomenological research studies which have been conducted with parents of autistic children who home-educate are those by Kidd and Kaczmarek (2010) and Hurlbutt (2011). A similar phenomenological research study with parents of autistic children who share education of their autistic child between home and an outreach education provision in Australia is that by McDonald (2010), further discussed and explored by McDonald and Lopes (2014). A summary of the themes of these various studies is given below:

| <b>Lawrence (this thesis)</b>   | <b>Kidd &amp; Kaczmarek (2010)</b>   | <b>Hurlbutt (2011)</b>   | <b>McDonald &amp; Lopes (2014)</b>   |
|---|--|--|--|
| <b>Theme One: Shared education is a response to need (both of child and of parents)</b><br>1.1: The concept of 'down-time'<br>1.2: Distress in the child<br>1.3: Building self-knowledge in the child<br>1.4: Parental choice | <b>Theme 1: Impact of school experience</b><br>Cognitive challenges<br>Anxiety and stress<br>Teacher's understanding of autism | <b>Theme 1: Parents ... are knowledgeable about ASD and are involved, watchful [and] want only the best for their children</b> | <b>Reasons for withdrawal from school</b><br>Ongoing negative socialisation (including bullying)<br>Insufficient academic progress<br>Failure of schools to understand child's profile |

1.5: The need for time

1.6: The 'big picture'

**Theme Two: Shared education is a response to the school experience**  
2.1: Problems with school  
2.2: Advantages of school

**Theme 2: Experience of coming home**  
Increase in well-being  
Individual learning needs met  
Flexibility

**Theme 2:** The specific situations and treatment programs ... are very diverse, unique, and individualized

**Strengths of at-home element of education**  
Life skills (cooking, washing, housework, caring for pet)  
Community/social undertakings (library, shopping)  
Independence  
Exercise (waking, riding, swimming)  
Tailoring of the curriculum to meet the child's interests and needs including practical supports such as acting as a scribe.

**Theme Three: Shared education is a bridge between home and school**  
3.1: Shared strategies  
3.2: Shared communication  
3.3: Shared success

**Theme 3: Mother's experience as educator**  
Multi-roles  
Forms of support  
Attitude or perspectives about home-education

**Theme 3:** Parents ... have different opinions about what needs to be addressed from what teachers and public school systems are doing

**Positives of school input into education**  
Academic input  
Social skills/communication  
Independence skills  
A 'break' for the parent-in-charge

**Theme 4:** Parents believe that homeschooling is a major decision and that both parents need to be in agreement with this choice

**Overarching theme:** Parents ... feel ... they have found a treatment plan that works, and ... the school has been either (a) not

willing and/or (b)  
unable to provide  
that treatment  
effectively.

*Figure 7: Comparison between findings of Lawrence, Kidd & Kaczmarek and Hurlbutt*

### **7.1.1 Kidd and Kaczmarek (2010)**

Kidd and Kaczmarek first explore the impact of the school experience.

#### ***7.1.1.1 Impact of school experiences***

Their finding that participants have experienced a discrepancy between the needs of their child as they understand them and what is offered to their child by the school is entirely borne out in the data collected in this current study, as recorded under Theme 2.2: 'Problems with school'. The impression reported by the parents in Kidd and Kaczmarek's study that their children are 'falling through the cracks' is echoed in DN's report of her frustration that the school could not recognise how Ben was underachieving while there. Kidd and Kaczmarek report one parent, Dawn, giving an example of her son struggling to move on from a task:

'The ... teacher would just [say], "Luke you've got to stop" and not give him a warning, and just turn the computer off on him while he is in the middle of something. So, he always needs to finish what he's doing, so they would turn it off, so he would sit there and start screaming and throw himself on the floor.'

This account bears strong similarities to the account which GE gives of Adpar:

'There was a particular incident where they were doing Maths and he was actually in a classroom and he was trying to work on this sum and, before he had the chance to do it, the teacher said, "Right everyone put your pens down we'll go through it" and he didn't want that ... and he said "no" and then the teacher decided, so he decided to try and threaten the teacher.'

Kidd and Kaczmarek report parents in their study indicating high levels of anxiety and stress in their children, and this is reflected in this study (Lawrence, 2017)



and recorded under the concept of distress in the child (1.2). Kidd and Kaczmarek particularly highlight the issue of the child experiencing meltdown at the end of a day spent at school, something which CY reports as happening to Coby before he started shared education. Dawn, in Kidd and Kaczmarek, reports that the school experience was 'very stressful for the whole family', which is echoed in reports by both DN and CY in this study.

#### ***7.1.1.2 Experience of coming home***

Kidd and Kaczmarek's 2<sup>nd</sup> theme, what they call 'The experience of coming home', describes the response by the families in their study to the removal of their child from the school system in order to home-educate. They report an increase in well-being for the child, who experiences less stress and gains both increased confidence and better social skills. This is similar to other reports into home-education with children with SEN (e.g. Parsons & Lewis, 2010; Kendall & Taylor, 2016), that parents identify their children as 'happier, more confident and far less anxious' when withdrawn from school to home-educate (Kendall & Taylor, 2016, p. 307).

Participants in this study similarly report increase in their child's happiness and DN particularly emphasises the health gains that Ben experiences by having time away from school. This feeling of increased well-being, of flexibility and of the opportunity for individual learning needs to be met is recorded throughout the study, and specifically as elements of Theme 1 ('Shared education as a response to need') in this study.

One of the strongest elements in Kidd and Kaczmarek's report which is echoed in findings in this study is the emphasis on the need for downtime (also called 'solitude time' in Kidd and Kaczmarek's report). This is reported in this study (Lawrence, 2017)

in section 1.1. DN also echoes findings in Kidd and Kaczmarek that home-education time is needed to enable the child to progress educationally and to 'reduce a lot of the issues that were preventing [him] from learning' (Kelly, in Kidd & Kaczmarek p 266.)

#### ***7.1.1.3 Mother's experience as educator***

The pressures on mothers enabling full-time home-education is explored as a theme in Kidd and Kaczmarek but does not emerge as a separate theme in this study, being identified specifically only by GE. An explanation for this may be that the mothers in this study are not providing full-time home-education; the shared element with the school may in itself be providing some relief from the pressures experienced by the full-time home-educator. Another potential explanation for the lack of reported 'pressure' on the majority of parents in this study (Lawrence, 2017) may be the vulnerability of their position. Shared education, unlike full-time elective home-education, is not a legal right, and the parents in this study seemed largely keen to emphasise the positives of what they were doing rather than to emphasise any additional stress that they were suffering. Even GE, who is not sharing education by choice, is keen to emphasise the positives even as she articulates the tremendous pressure she is under. In her case, this appears to be because of her fear that, if she is not able to continue to share Adpar's education and thereby relieve pressure on the school, the school will exclude Adpar totally.

#### **7.1.2 Hurlbutt (2011)**

Hurlbutt's study identifies four themes, together with the overarching theme, which again set up echoes with this current study, although again findings are not precisely aligned.

##### ***7.1.2.1 Theme 1:***

**Parents ... are knowledgeable about ASD and are involved, watchful [and] want only the best for their children**

Hurlbutt's first theme, that parents who homeschool their children with ASD are knowledgeable about ASD is mirrored in the findings in this study, although it does not emerge as a separate theme. Rather, parental knowledge about their child's autism is implicit in much of what is reported and all parents in this current study show strong autism awareness. Parents in Hurlbutt's study report difficult experiences when their child was pre-school age, a finding which is echoed in reports by SS, DN and GE in this study.

#### **7.1.2.2 Theme 2:**

##### **The specific situations and treatment programs ... are ... diverse, unique, and individualised**

Hurlbutt's report (2011) includes surprise that the home-schooling goals and interventions vary so widely across the families who took part in the study (theme 2). The list of goals given across the ten children in her study is no more diverse than those suggested in this study, and indeed many of the indicated goals are duplicated (see Table 3 below).

##### **Summary of Hurlbutt's list of parental goals for home-education:**

To provide the opportunity to properly follow a special diet  
 To support academic progress  
 To avoid labelling as autistic  
 To facilitate a learning environment that addresses both the child's gifted and developmental demands  
 To allow for multiple breaks during the day  
 To help the child to reach his potential  
 To increase attention and language skills to learn self-advocacy  
 To work to decrease sensory sensitivities  
 To facilitate language development  
 To increase positive behaviours and decrease aggressive behaviours

##### **Duplication in this study of parental goals for shared education:**

To support academic progress  
 To facilitate a learning environment that addresses both the child's gifted and developmental demands  
 To allow for multiple breaks during the day  
 To help the child to reach his potential  
 To increase attention and language skills to learn self-advocacy  
 To work to decrease sensory sensitivities  
 To facilitate language development  
 To increase positive behaviours and decrease aggressive behaviours

|  |  |
|--|--|
| <ul style="list-style-type: none"> <li>To facilitate social interactions and increase social skills</li> <li>To provide structure</li> <li>To aid the eventual transition back to school</li> <li>To learn how to make his way in the world</li> <li>To provide flexibility in scheduling</li> <li>To provide structure and routine</li> <li>To facilitate independence</li> <li>To teach life skills</li> </ul> | <ul style="list-style-type: none"> <li>To facilitate social interactions and increase social skills</li> <li>To provide structure</li> <li>To aid the eventual transition back to school</li> <li>To learn how to make his way in the world</li> <li>To provide flexibility in scheduling</li> <li>To provide structure and routine</li> <li>To facilitate independence</li> <li>To teach life skills</li> </ul> |
| <b>Goals suggested in Hurlbutt not indicated in this study:</b>  | <b>Goals suggested in this study not indicated in Hurlbutt:</b>  |
| <ul style="list-style-type: none"> <li>To provide the opportunity to properly follow a special diet</li> <li>To avoid labelling as autistic</li> </ul>   | <ul style="list-style-type: none"> <li>To 'break up' the week</li> <li>As the only school-time available to the pupil (either because of pupil elements or school elements)</li> <li>To access autism-specific provision</li> <li>To de-stress in order to manage the demands of the other days in school</li> <li>As a way of maintaining health (mental or physical)</li> </ul>                                |

*Figure 8: Comparison between goals for home-education as expressed by Hurlbutt and Lawrence*

As seen in the table, there is considerable duplication between the goals of home-education of their autistic child as expressed in Hurlbutt's study, and that of shared education as expressed in this study (Lawrence, 2017). Indeed, the only goals indicated in Hurlbutt and not in this current study are the wish to follow a special diet and the wish to avoid being labelled. The absence of each is logical: none of the children in this study was following a specialist diet so the issue did not arise, and the option of shared education relies not just on disclosure but on a readiness to put the child's autism needs to the fore. It follows, therefore, that the parents who volunteered for this study and who had negotiated a shared education due to their child's autism were not concerned about issues of disclosure.

Goals indicated in this study but not in Hurlbutt are noteworthy. They include to 'break up' the week; as the only school-time available; as a way to access autism-specific provision; to de-stress in order to manage the demands of the other days in school; and as a way of maintaining health.

Two of the participants in this study (Lawrence, 2017), TE and CY, engage in one at-home day per week, in each case on a Wednesday, in order to 'break up' the week. In direct contrast, two other participants, GE and DN, describe provision where their sons attend school for a rather minimal time (for one and a half hours each day in the case of Adpar and for one hour twice a week for Ben). Ben is reported as unable to tolerate further at-school time without becoming ill, and GE reports that the school requires Adpar to attend for no more than the currently offered hour and a half. Both DN and GE would prefer that their children could increase their at-school time. SS uses the at-home element (which takes place now in the unit she has founded) to provide autism-specific input for both Edward and Eloise. Her motivation for sharing education seems primarily to facilitate the provision of these inputs which are not available in either mainstream school or the non-autism-specific special school in her area. CY sees the at-home element as an opportunity for Coby to de-stress in order to manage the demands of the other four days at school. DN articulates the at-home time as being a way of maintaining Ben's health which experience suggests would be adversely affected by more time spent in school.

#### **7.1.2.3 Theme 3:**

**Parents ... have different opinions about what needs to be addressed from what teachers and public school systems are doing**

Hurlbutt's third theme is interesting in identifying that parents have different opinions from teachers and school systems about what needs to be addressed in 'education' for a child with autism. This feeling that the curriculum of school is not

necessarily the most useful curriculum for children with autism is one repeated in this study (Lawrence, 2017). Hurlbutt reports parents' desire for their child to learn to function within society, a priority which SS, in this study (Lawrence, 2017) shares as important. TE is also concerned that Elliot's learning should include elements of self-awareness and how to self-regulate as being just as important as an academic curriculum.

#### **7.1.2.4 Theme 4:**

Parents believe that homeschooling is a major decision and that both parents need to be in agreement with this choice

There is little suggestion relating to theme 4 of Hurlbutt's study, that parents who homeschool their children with ASD believe that home-schooling is a major decision and no data that both parents need to be in agreement with this choice, is evident in this current study. Shared education could, arguably, be just as major a decision as home-education, but none of the parents in this study make reference to their own positions in this way. One explanation for this may be for a similar reason as that suggested for the absence of comments aligned to Kidd and Kaczmarek's Theme 3: the vulnerability of the shared educators' position within their legal right to share education.

#### **7.1.3 Differences between findings in this study (Lawrence, 2017) and other studies into home-education with children with autism**

Where the data from the two home-education studies differs from that in this shared education study is in what is identified under theme 2.2 ('Advantages of school') and theme 3 ('Shared education as a bridge between home and school'). Perhaps because Kidd and Kaczmarek, and Hurlbutt are researching parents who have withdrawn their children with autism completely from school, there is little data in their studies regarding positives elements of school attendance. However, there may be indications in their studies that the parents would not reject school so comprehensively

if given the option, and that they have some awareness of the potential advantages of a 'bridging' between home and school. Sally, in Kidd and Kaczmarek (p268), reports:

'...it's tough on me to both have to manage and teach him, to manage his anxiety, manage his disability, look after him as a mother and educate him, that's one hell of a job.'

Kidd and Kaczmarek report that, whilst some mothers did not indicate a need for education support, others had tried to access this support but without success. What is not clear in this data is the question of whether, should shared education have been given as an option to these mothers, any would have considered it. The report by Dana (Kidd & Kaczmarek, 2010, p. 268) of her feelings of isolation and how she 'keep[s] ringing up and saying, "help me, help me!"' would suggest that she would have welcomed more input into her son's education from the school had it been available to her.

This ambiguity as to whether shared education might have been considered if offered to the parents in the home-education studies is present also in Hurlbutt's study. The emphasis on the potential stress and the commitment – both financial and social – that is needed to home-educate may itself imply that these parents would welcome some school support if they felt it could be made appropriate.

A further finding is that Hurlbutt identifies as her overarching theme that the parents who homeschool their children with autism in her study felt that they have found a treatment plan that works. This is echoed in the unanimous endorsement of shared education as being 'of benefit' to the child with autism found in this study (Lawrence, 2017). However, whilst the parents in this study do all report that they feel that shared education as experienced by them does work, it is important to note there is not the same sense of satisfaction with the provision as is evident in Hurlbutt's study. In

this study (Lawrence, 2017), CY is happy with shared education, but would prefer to extend it; SS is happy with the home-based element, but is setting up a school to better provide autism specific input for the school-based part of her children's education; TE enjoyed shared education and was satisfied by it, but has not been able to continue with it as the school did not allow it; DN is sharing Ben's education because she fears for his health if she does not, and is fighting to keep him in the education system rather than having Ben totally home-educated; GE would rather that Adpar's needs were met fully at school, and is sharing education at the request of the school and not electively. Where the parents in Hurlbutt's study are happy in their (legally secure) position as home-educators, the shared educators in this study appear less secure and less settled.

The parents in all three studies (Kidd & Kaczmarek, 2010; Hurlbutt, 2011; Lawrence, 2017 (this thesis)) see their children as individual and are keen to meet the child's needs individually. Indeed, much of the frustration with schools exhibited in these studies is around the inability of school to treat their child as an individual, and frustration with stereotyped and non-child-centred perceptions of autism as displayed by “experts”. CY argues, 'I don't know what a classic case of ASD is, but from the children I've met ... [Coby]'s completely different' and SS says:

'One of the frustrating things ... is the stereotypical view of autism: ... “He's autistic therefore he needs PECS now; he is a visual learner; he needs routine; he'll have ritualistic behaviours blah blah blah”. They'd wheel it out.'

There is a powerful impression in each of the studies that parents view their child as more than a standardised set of criteria, especially negative criteria, and that they perceive the need to deliver an individualised education to their children which addressed their individual autism needs.



There is also some suggestion in the data from all three studies of frustration regarding the role that parents have had to assume as curriculum educators. There is consistent report in the studies that the schools involved are not teaching these children in the way that they learn. Kidd and Kaczmarek report that, 'One of the main reasons behind mothers' decision to home-educate was the discrepancy between the learning needs of the child and the learning programmes offered at school' (p263). Kidd and Kaczmarek further report that eight out of the ten mothers in their study mention the atypical learning style of their children as a factor in withdrawing them from school. Many of the mothers in Kidd and Kaczmarek's study discussed 'concerns over their child's future academic outcomes', indicating, for example, where home-education has 'reduce[d] a lot of the issues that were preventing them from learning' (p. 266). These concerns about academic progress are echoed in this study: 'I don't want him falling behind' (GE); '[home school is about] learning in an environment that doesn't exhaust him' (CY).

While the parents in Kidd and Kaczmarek and Hurlbutt's studies have addressed this problem by removing their child from school, this is not always shown to be something with which parents are at ease. Kidd and Kaczmarek report concerns felt by the mothers in their study on the difficulty of 'juggling of roles required of them' (p. 267) and Hurlbutt reports one parent's indication that taking the child out of school is 'hard on the family, a huge sacrifice' (p. 246). Kidd and Kaczmarek report one parent's frustration at lack of support from school: 'There is a huge amount of support in the school situation that you don't have as a homeschooler ... I've needed it, it's not available.'

These findings are echoed in this study (Lawrence, 2017), where parents are working hard to try to maintain their child's access to the school curriculum. CY feels that Coby is not learning at school because of his autism and that, although she understands Coby's autism needs, she is not qualified to teach him and so has employed a tutor during his at-home day. This is echoed in Hurlbutt's research where a number of the parents have employed a private tutor to deliver academic content 1:1. DN is keen that Ben should be able to access teaching at his academic level without the stress of doing this through school making him physically ill, and is investigating access to a supported college place as well as accessing online university materials. GE would very much like Adpar to be able to go to school and learn, but feels at the moment that the provision of withdrawing him to a room on his own with an unqualified 1:1 assistant is not enabling that learning, even in the time that school allows him to attend. SS has been keen since Edward was born to develop her own understanding of, and expertise in, his autism and wants him to be able to access autism appropriate teaching at his special school.

There is also a suggestion emerging from the parents in these studies that many feel that schools are not able to adapt to meet the needs of the child unless the child adapts to meet the needs of the school. The parents in the two home-educating studies are not necessarily rejecting school; Kidd and Kaczmarek report that parents in their study 'for the most part ... did not have negative comments to make about the school system; it was just that programming in the schools was not the best fit for their child' (p. 247). This feeling of what is being offered by the schools as not being a 'best fit' is strong in this study (Lawrence, 2017). There is a frustration that schools may have a preconceived notion of how to support a child with autism, without reference to the individual needs of the actual child. Indeed, SS recounts that she has 'even had Speech

and Language plans where they forgot to change the name.' Individual participants are keen to counter a purely negative impression of their child's autism, and rather to indicate what they see as being their child's strengths. CY reports that for Coby to be able to go to (mainstream) school he is expected to overcome issues presented by his autism such as sensory sensitivity to assembly or the dining hall. SS's frustration with the special school that Edward now attends in the mornings is that it is generic, and does not adapt provision to meet Elliot's specific autism needs. Ben's school, by DN's report, cannot adapt to a point where Ben can attend without becoming ill. In GE's case the school is apparently incapable of accommodating Adpar as he is, and is deferring their responsibility to educate him back to his mother.

Inherent in the “big picture” of their child's education as presented by the parents in all three studies examined here is a fear of what will happen to their children if they do not 'step in' to their education. Indeed, stronger even than any impression of conviction in the parents in these studies that there will be positive benefit if they either fully or partially take on responsibility for their child's education is the fear of what will happen to their children in the future if they do not.

#### **7.1.4 McDonald (2010), and McDonald and Lopes (2014)**

McDonald's doctoral thesis (2010), an 'investigation into how parents deal with the education of their child with an ASD over time', includes a section which examines the experience of two parents of children with autism who home-educate with the support of the Schools of Isolated and Distance Education (SIDE) in Western Australia. This data on the experience of these two parents is additionally and more specifically explored in McDonald and Lopes' paper of 2014 on the reasons for the parents' withdrawal of their autistic child from the school system, the parents' perceptions of the

benefits for their child of the at-home element of their education, and their perceptions of the strengths of the at-school element provided by SIDE.

#### ***7.1.4.1 Reasons for withdrawal***

Reported reasons for withdrawing the two autistic children in McDonald's study from school include concerns regarding ongoing negative socialisation (including bullying), insufficient academic progress and the failure of the schools to understand their child's profile. The emphasis on negative socialisation and bullying echoes concerns expressed in both Kidd and Kaczmarek's study and in Hurlbutt's study, but is not echoed by the participants in this current thesis. However, concerns about insufficient academic progress and failure of the school to understand the child as an individual are both themes which are fully reflected in this study's findings.

Each of the families in McDonald's study reached a 'crisis point' which resulted in the child's withdrawal from school. For one of the children this crisis point was the expression of suicidal ideation and in the other it was bullying to an extent that warranted police involvement so that the parents felt that their child was 'no longer safe' (McDonald p. 229). The parents in this study (Lawrence, 2017) do not articulate reaching a 'crisis point' with quite such clarity, although there is frequent indication that there came a moment – a 'tipping point' – which was the trigger for moving to shared education. For CY, this moment was when the school used physical force to compel Coby into school; for DN it was the crisis of Ben's physical illness; TE responded to Elliot's distress, particularly to his reported stomach aches; and for SS the 'trigger' was her growing awareness of the lack of specialist experience and equipment for Edward at his mainstream school. GE's experience differs in that Adpar's shared education is at the request of the school rather than because she has negotiated it.

#### ***7.1.4.2 Strengths of at-home element***

The strengths of the at-home element of the education as identified by the parents in McDonald's study include life skills such as cooking, washing, housework and caring for pet; community and social undertakings such as visits to the library or shopping; opportunities for exercise such as walking, riding and swimming and, more generally, increased independence. They also include the opportunity for the tailoring of the curriculum to meet the child's interests and needs, and to provide practical supports to the child's academic work, such as acting as a scribe.

Similar perceptions of the strengths of the at-home element of shared education emerge strongly from the findings of this study (Lawrence, 2017). Both CY and GE mention cooking as an at-home element, and Elliot mentions both cooking and running as elements of his at-home education which he enjoyed. DN articulates how Ben's at-home time has enabled him to increase his independence and navigation skills, and SS places a strong emphasis on Edward's need to experience a natural social environment, and to develop acceptance of elements of daily life such as visits to the doctor and dentist, and having his feet measured for shoes. This awareness of their child's wider educational needs by the parent, and the opportunity for a tailored, supported and individualised wider curriculum is an element of autism education articulated by each of the parents in this study (Lawrence, 2017). Additionally, the parents' wish to support their child with an academic curriculum is also voiced. CY has employed a tutor, and is confident that this tutor's 1:1 style of teaching is greatly supporting Coby's learning; DN is enabling Ben to access university-run courses, together with supporting him with his independent at-home learning; TE mentions 'basic academic things that I wanted to work on' with Elliot. Part of GE's distress that Adpar is not being given access to teaching in school, but instead being 'contained' 1:1 with a TA, is that he will fall

behind academically, and is trying to support his academic learning herself. SS places less emphasis on academic learning with her children, but articulates clearly that for them skills such as language acquisition, or the use of an alternative communication techniques, are essential skills and should constitute part of their the ‘curriculum’.

#### ***7.1.4.3 Positives of school input***

In each of the two cases reported by McDonald, the support of SIDE is reported to have 'lightened the load of the person-in-charge of the home-schooling programme and helped them to sustain their efforts towards the progress of the child with an ASD' (McDonald & Lopes, 2014, p. 10). The extent of SIDE input within the two flexi-schooling models described varies from one half day a week to two full days per week, with the levels of involvement in each case evolving over time. To this extent, the ‘outside’ involvement in McDonald’s research is concordant with that in the school input in this study (Lawrence, 2017). School involvement in this study varies from a minimum of two hour-and-a-half sessions per week (Ben) to a maximum of four full days each week (Elliot and Coby).

The extent to which at-school time can be seen to ‘lighten the load’ of the parents in this study (Lawrence, 2017) varies. GE articulates clearly that the extent to which the school are ready to ‘lighten the load’ for her with Adpar to be limited, describing how she needs to bring in additional support to sit with her disabled husband when the school requires her to attend with Adpar at school, and how the ninety minutes per day which school does provide without her being there to be ‘barely time to walk home and have a cup of tea’ before it is time to go back. TE describes satisfaction with the time provided by the ‘alternative special school’ which she found for Elliot, as SS does equally with the input of the autism provision which she has co-founded for her children, but each – together with CY, DN and GE – describe how awareness when

their child is or was at an inadequate provision, and is unhappy, does not 'lighten the load' of their responsibility for meeting the needs and welfare of their child in any way.

#### **7.1.5 Differences between findings in this study (Lawrence, 2017) and that of education shared between home and SIDE for children with autism**

SIDE is reported by McDonald to provide support with the academic curriculum of the two children in her study, allowing the child 'access to a wide variety of high school correspondence courses' (p. 12) and a tailored education process 'around the needs and interests of the student with an ASD' (p. 237) and the child's 'individual learning needs, interests and comfort level' (p. 235). The flexibility of the SIDE curriculum is reported to be 'a great support' and 'very flexible and accommodating' (p. 10).

In contrast, the school element of the shared education as explored in this study (Lawrence, 2017) is described as neither individualised nor adapted, with the 'flexibility' being provided by the fact of the shared education rather than through elements of adaptation in the child's education by the school. The pupils' at-school days in this study require them to continue with the curriculum and learning delivery as decided by the school, often without further adaptation to meet their specific autistic needs. There is little belief evident in the participants' reports that the curriculum as offered to their children in the at-school element of their shared education is tailored to their individual learning needs nor interests, nor that there is accommodation made to enable their sensory or communication needs to be made more comfortable. Where SIDE in Australia is offering an individualised and personalised programme of study for the at-school element of the children's education, the children in the UK study are continuing to access school 'as is', even when both the environment and the academic delivery are considered by the parent to be inappropriate.

Nonetheless, the parents in this study (Lawrence, 2017) continue to indicate a wish for their child to have access to school, both for academic input and for access to a social environment.

A significant benefit of SIDE involvement in the education of the children in McDonald's study is reported to be the social input of an 'open and trusting relationship ... established over time between the staff at SIDE and the parent and student with an ASD' (p. 236), together with the opportunity to 'practise ... social skills in a supported, supervised, mainstream, adult environment' (p. 235). Strong communication is highlighted by McDonald as important in a situation where 'both parent and child with an ASD ... gradually gain trust in the teacher ... [and] communicate openly about the student's difficulties' (p. 236).

In the case of Coby's tutor, LL, a similar trusting relationship appears to have been established, and TE similarly reports good communication and strong elements of trust in her relationship with Elliot's special school. Strong communication and trust are highlighted by SS as essential components of the education offered by her autism unit, and CY, DN and GE each articulate examples where an open and trusting relationship either exists currently or has been established between them and their child's 1:1 support assistant in the past. Communication difficulties between home and school, however, remain a highlighted difficulty in the reports of each of the participants in this study (Lawrence, 2017).

There is also some indication in McDonald's study that peer support is enabled for the pupils using SIDE, where staff 'actively encouraged relationship-building among the students who attended the main school site on common days of the week' allowing 'positive youth friendships to emerge under the guidance and supervision of staff



members at SIDE' (McDonald and Lopes, 2014, p. 11). Where peer relationships have been suggested to be a concern for the parents in this study (Lawrence, 2017), there is no indication that the school are using the reduced pupil contact time to facilitate the creation of more active peer support for these children.

The chance to develop independence was highlighted in each example of McDonald's study with both students being encouraged to attend the SIDE main site during the week (which is not the usual case for the distance-learning students) in order 'to become more independent, socially able and gain direct feedback' (McDonald & Lopes, 2014, p. 10). This had the added advantage of enabling a break for the parent-in-charge ('gave this parent some much needed respite', *ibid.*, p. 236), because the parent felt that the child was safe 'I ... know that he was in really good hands' (*ibid.*, p. 237).

The emphasis on respite only being valuable where the child's needs are being satisfactorily met is echoed, as discussed, in this study (Lawrence, 2017), as is the degree to which shared education can support independence. In contrast, though, where McDonald's participants suggest that it is the at-school element which supports independence, in this study the participants articulate that it is the at-home element which is supporting this independence, through the supporting of skills such as orientation (Ben) and self-care (Edward), or through enhanced understanding of their own autism and, consequently, self-regulation and self-awareness (Elliot, Ben, Adpar and Coby).

#### **7.1.6 Interim summary: Comparison with other studies**

All four studies (Kidd & Kaczmarek, 2010; Hurlbutt, 2011; McDonald & Lopes, 2014; and Lawrence, 2017 (this thesis)) emphasise the parents' wish to see their child as an individual, with individual needs. Each study reports that the participants feel that

their child was making insufficient progress in (full-time) school, and that they believe there was a failure by the schools to understand their child's profile.

None of the studies suggests that parents are rejecting school per se, but rather that they have found it to be an inappropriate environment for their autistic child. Indeed, there is frustration evident in all four studies that the parents are having to provide academic support, for which they do not feel qualified and which they would prefer that school should provide, if it could do so in a way accessible to their child and delivered at an appropriate level for their child. This is relieved somewhat in the study by McDonald and Lopes, who report that SIDE offers them practical support with their child's academic curriculum.

All studies emphasise the positives of at-home time, including the opportunity to learn life skills, to enjoy participation in the community, to share in exercise and social activities together and to tailor the child's learning to better meet his interests and needs.

In each of the studies motivation for parental involvement includes the perceived discrepancy between the parents' understanding of the needs of their child and what is offered to their child by the school. In each study parents are responding to high levels of anxiety and stress in their children engendered by school, and in each the withdrawal from school (even the partial withdrawal as reported in Lawrence) results in perceived increased well-being for the child.

Hurlbutt and Lawrence, specifically, report similar findings on the extent to which the parents in their studies are knowledgeable about autism. There are widely varying goals reported to be the purpose of the parental intervention in the studies, but these show broadly general agreement. There is indication across all of the studies that

the parents hold different opinions from school authorities about what needs to be prioritised in 'education' for their child with autism.

Where findings from this study (Lawrence, 2017) diverge from those of the others is in the extent to which parents report on their perceived positives about continued access to school, although McDonald and Lopes report participants to be extremely positive about what is offered to their child by SIDE. There is no indication in Lawrence, as there is in each of the other three studies, that parents have withdrawn their child because of negative socialisation and bullying.

The parents in McDonald and Lopes' study on shared education enjoy an open and trusting relationship with SIDE, something which the parents in Lawrence's study seem to be struggling to achieve. Nor, unlike in McDonald and Lopes, is there much indication in the report of parents in this study (Lawrence, 2017) of a flexibility of approach being offered, or that their children are being given support to form and maintain peer relationships during their at-school time. The parents in this study seem also to be less secure in what they are doing than those in each of the other three studies, and, perhaps because of this, are less ready to report that they are experiencing pressure or to describe their involvement in their child's education as being a major undertaking.

Perhaps most striking is that McDonald and Lopes' study into shared education with SIDE reports a benefit of that shared education to be a 'lightening of the load' on that parent-educator. These parents start from a position where they have withdrawn their child to full-time home-education, so that the shared education element, which they perceive as flexible and tailored to meet their child's needs, 'lightens the load' of their full-time home-educating commitment. In contrast, the parents in this study

(Lawrence, 2017) seem to frame the shared education more in terms of their ‘lightening the load’ of full-time schooling for their child. Where in McDonald and Lopes’ study, the parents feel able to ‘off load’ some of the responsibility of meeting their child’s needs onto SIDE, in this study (Lawrence, 2017) the language is more about the parents taking on some of the load of full-time school as experienced by their autistic child.

## **7.2 THIS STUDY’S CONTRIBUTION TO KNOWLEDGE**

The findings of this study as presented under the super-ordinate themes and considered in comparison with findings in similar studies into parents providing or sharing the education of their autistic child can be taken holistically as a contribution to knowledge. This contribution recognises that shared education is meeting a need, that it is undertaken in response to the school experience of the child, that it is functioning as a ‘bridge’ between various aspects of the child’s life and that it is providing a way for parents to overcome the potential barrier which autism may create in their involvement in their child’s education.

### **7.2.1 Shared education is meeting a need**

#### ***7.2.1.1 Child’s need for protection and parents’ need to protect child***

The first theme to emerge from this study (Lawrence, 2017) is that parents feel that in sharing the education of their autistic child they are meeting a need, in their child and – less palpably – in themselves. The parent’s need in each case is articulated as a powerful urge to protect her child or children, and her impression that this protection is necessary. All of the participants in this study are mothers, and there have been various studies (e.g. Noriuchi, Kikuchi & Senoo 2008, Graham, 2004) which suggest a biological basis for the strong maternal protective instinct. This theme articulates the participants’ perceptions that the reduction in their child’s school time and/or the increase in their child’s at-home time is meeting a need in that child. This need is

articulated by participants most frequently in terms of distress in their child, although it is also indicated by parents' perceptions of fear for the child's future.

#### ***7.2.1.2 Parents' need to react to child's distress***

The data gives compelling examples of the mothers in this study reacting to the communication of distress by their children. The parents' rationale for intervening in their child's education due to the child's distress is in only one case in this study reported to be due to verbal communication by the child ("He was saying that the week was too long" - TE) but in three of the five cases is in response to perceived distress observed by the parent in the behaviour of their child. One manifestation of this distress is 'traditional' (Coby is described as crying at night time), but at other times is manifested in the study as illness. TE reports that Elliot felt sick and CY, whilst accepting that Coby's illnesses were 'feigned', nevertheless took them seriously. DN reports dramatic illnesses in Ben, regression in his behaviour and loss of skills.

#### ***7.2.1.3 Parents' increased sensitivity to child's communication***

The parents' intervention may be instigated in response to their increased sensitivity to the child's distressed communication. CY reports this distress as being manifested in 'shutting down' at the end of the day, a finding which is supported in the literature in Kidd and Kaczmarek's report of a child experiencing meltdown at the end of a day spent at school. 'Sally', in Kidd and Kaczmarek, reports:

...sometimes he'd come home from school and after he'd yelled and screamed and threw his bag and punched me he'd then go to bed and cry himself to sleep and sleep for 2 to 3 hours. And that often happened every day' (p264).

CY similarly reports:

[Coby] just literally shut down ... and then it would all come home to me, you know? ... and he was probably having at least one or two days a week, when he just physically couldn't go in...

#### ***7.2.1.4 Parents' high levels of knowledge about their child***

The participants' understanding of the need for this protection is articulated in the degree to which the mothers in this study display high levels of knowledge about their child and have confidence in their understanding of their own child (for example, '[I] felt I knew my son best', TE; 'I know a lot more about my child', GE). Hurlbutt, and Kidd and Kaczmarek each report a similar impression given by the parents in their studies that they know their own children best (for example, 'parents know their child better than anyone else does', Kidd and Kaczmarek, p. 247). All the participants in this study (Lawrence, 2017) show strong autism awareness, and some – most strikingly SS – have a knowledge which could be considered to exceed that of many education professionals. This is consistent with the first theme described in Hurlbutt's study (2011).

In line with this, SS, CY and DN all recount early awareness of autism in their child ahead of professional acceptance of it. SS's experience of being told about Edward that he was not autistic but 'just wasn't being stimulated' is echoed by the response of several parents in Hurlbutt's study who were 'told to wait' or that they were 'overreacting' by pediatricians or other professionals (p. 244). GE's experience with Adpar at nursery where he 'ended up hitting some children and shouting at teachers and ... I had to go and collect him' is echoed in Hurlbutt's study where one parent reports being asked to collect her son from daycare, saying that 'Chris failed daycare after 7 hours!' These frustrations are in line with research results which suggest that parents are able to identify early signs of autism, with 38% of parents in one study recognising

autism concerns within the year of life and 78% within the first 24 months of life (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003), itself concordant with findings in an earlier study (Lord, Rutter & Le Couteur, 1994). It seems that, despite Lamb's recommendations that parents of children with SEN should be listened to and despite government initiatives (for example, DCSF 2007; 2008; 2009), parents may still be struggling to be heard.

## **7.2.2 Shared education is as a response to the school experience**

### ***7.2.2.1 Concerns at lack of academic progress***

A lack of academic progress, or the unsuitability of either the learning content or delivery at school, is cited frequently as a reason for the parents 'stepping in' to their autistic child's education. CY reports that Coby is not learning at school, DN is concerned about the academic level of education provided by the autism unit available to Ben, and GE reports that Adpar is withdrawn to a room with his 1:1 and is not learning during his short time at school each day. In this GE's experience echoes that of 'Parent D' in Kendall and Taylor's study (2016) into the reasons for parents to withdraw their child with SEN from school to home-educate. In this, the mother reports that getting her autistic son the support of a TA was 'an excuse to get him out of the classroom ... she had not trained in ASD and would take him into the corridor. He was really bright but was spending most of his time informally excluded' (Kendall & Taylor, 2016, p. 306). Similarly, Hurlbutt (2011) reports that one of the parents in her study, 'Lana', believed that 'the teacher stopped trying to teach [her son] anything' when his behaviour became unruly (p.245), and Kidd and Kaczmarek describe the 'discrepancy between the learning needs of the child and the learning programmes offered at the school' as one of the main reasons given in their study for parents to choose to home-educate (p. 263). The parents in each of the studies are reporting

insufficient academic progress, lack of cognitive challenges and the inability of their child to access school learning as reasons for their intervention.

#### ***7.2.2.2 Schools not perceived as providing 'suitable' education***

The participants in this study (Lawrence, 2017) are very clear in their own minds what the problems are with full-time school. This may be that the school environment is itself damaging, or that it simply does not deliver the curriculum that they envisage as important for their child. There is a frustration expressed by many of them that the school's concept of 'the needs of the autistic child' are too generic, and do not correspond to their own child's profile. They do not see their own children as 'typical', but as individual, and with individual needs. In SS's case, the 'special' school which Edward attends is not specialist enough, since it is a generic provision for pupils with Severe Learning Difficulties which does not have any autism-specific provision as part of its curriculum, and for TE, the flexibility to meet Elliot's needs was only found in a very small, 'alternative' private provision. For the other three participants, there is frustration that schools are either seen as 'mainstream' (and, as such, ill-equipped to understand the autism needs of their child) or 'specialist' (and, as such, ill-equipped to meet the academic needs of their child). These participants each value their child's intelligence highly, and see it as being as important in their child's profile as his autism – indeed, as being intrinsic to it. This valuing of the difference of autism is one element that they identify as frustrating in the way they perceive school as either hiding or disregarding autism, or seeing it only as something needing remediation, but not as something to nurture and value.

#### ***7.2.2.3 Parents are working hard to maintain access to school***

Although there is very real frustration about the school environment expressed by the participants, each is working hard to enable their child to continue to have access



to it. In the case of CY, although the at-home element of the shared education is only one day, it is this one day which she identifies as being what enables Coby to access school on the other days. The at-home element provides the release of tension which makes the other four days tolerable. DN and GE are, on the other hand, working hard to maintain the rather small amount of school contact that their child is accessing. In GE's case, she is accepting the minimal input by the school as the only alternative to total exclusion, since the school is unwilling to offer Adpar any more hours. In DN's case, any more time in school results in severe illness in Ben, who is only just recovering from the 'crash' which he experienced when forced to attend full-time at the move to secondary school. Again, the small input which he does tolerate is seen by DN as a way of maintaining a 'foothold' rather than settling for full-time Elective Home-education. SS is very aware of all the elements that she sees as essential for Edward's progress, both social and practical, and is combining the at-school element of the generic special school and the delivery of more targeted support through the centre that she has founded. TE, unable to persuade the small independent school that Elliot had been attending to let him continue beyond Year 9, had to choose between full-time school and full-time home-education. She chose school, she indicates, as this leaves the option of switching to home-education open if needed, where the other way around is more difficult to manage.

#### ***7.2.2.4 Parents' frustration that their input may be reducing school's perception of child's needs***

One of the most powerful reasons for anger expressed by the participants in this study (Lawrence, 2017) is that the work that they have done to support their child is they believe, perversely, leading to lack of provision for their child. They each report working hard to help their children to adopt socially acceptable behaviour. In the cases of CY, DN and SS, this is reported to mean that their child's needs are not recognised.

Autism is identified by behaviour and the parents are recognising the apparent dichotomy of helping their child to display more socially acceptable behaviour (being polite, not lashing out, sitting quietly) and in doing so risking that their child's autism needs are marginalised. Although they articulate frustration at this, the alternative – as witnessed by GE – is that their child is rejected because of his behaviour. Her frustration is that the school is unable or unwilling to adapt to or to accommodate behaviour which she reports to be living with every day.

#### ***7.2.2.5 Parents' perception of school as source of academic input***

One reason cited to retain access to school is that it is a way of maintaining access to academic input. GE says that she does not want Adpar to fall behind because he is out of school; DN is keen that Ben maintain a 'foothold' in the system, and CY expresses her feeling that she is not qualified (nor able) to provide the academic input that Coby needs herself. Although they articulate how their child is struggling to access learning at school at the appropriate academic level, they see the home-based element of shared education as supporting learning and as enabling their child to continue to learn in school. Both DN and CY comment on the extent to which their children learn academically away from school, Coby through the input of the home tutor engaged by his parents, and Ben through self-study and through remote learning courses, but parents indicate also how shared education supports access to school. Both CY and TE indicate that the break in the week given by the at-home day enables their sons to manage the other days in school, so that the break is in effect enabling the child to remain a pupil on the other days, and CY articulates specifically how Coby's tutor can prepare Coby ahead of new learning to enable him to better access it at school.

This emphasis on the advantage of accessing school – or externally provided education – for academic input is echoed in McDonald and Lopes' study into parents

who share the education of their autistic child between home and the SIDE provision, describing SIDE as being a measure which helps their efforts as parents towards the progress of their child. Both parents in McDonald's study value the academic input which SIDE provides, and particularly the flexible and individually-tailored way this academic curriculum is presented 'around the needs and interests of the student with an ASD' (McDonald, 2010, p. 237).

#### ***7.2.2.6 Parents' perceptions of school as a source of social input***

Important also to parents in this study (Lawrence, 2017) is the social input of school. SS is very keen that Edward and Eloise have access to their peers and works to support peer interaction; DN articulates how important it is to her that Ben be with children his own age, and GE is angry that Adpar's isolation is reducing his access to children his own age. Both parents in McDonald's study into shared education with SIDE report the advantages of the social input of the education provision. They indicate how the careful scaffolding of peer-interactions by tutors enable 'positive youth friendships to emerge under the guidance and supervision of staff' (McDonald & Lopes, 2014, p. 11).

### **7.2.3 Shared education is a 'bridge'**

#### ***7.2.3.1 Parents as a 'bridge' between child's needs and school provision***

Despite their apparently weak position legally, the parents in the study remain powerful in their defence of their child and in their articulation that they will enable the links between home and school for their child which they believe are essential. Their articulation of their child's communication of distress is moving, carrying with it as it does their frustration that it may not be believed by the school, and they are clear that they are trying to 'speak for' their child and to get that child's needs recognised and met. There is an articulation of the challenges of autism – sensory, language, social,

executive functioning, issues of central coherence, theory of mind – which are described by each parent as 'new' in their own child, as something that they have come to understand as an issue but which they fear that school does not understand or accept.

Important also to the parents in this study is that their children's needs are dynamic and not static. There is an urgency in what they do; they are aware that their child is an individual, not representative of the sample 'autistic', and that he or she is growing older every day. There is frustration at delays caused by the perceived slow movement of officialdom, and a palpable fear for the future if they do not 'step in' and form a bridge between their child and his or her education. Their confidence in their ability to do this varies, but they share a ferocity in their willingness to try.

#### Anxiety

Anxiety is reported in their child by DN, GE, CY and TE in this study, which is in line with other studies into the school experience of children with autism (for example, Parsons & Lewis, 2010; Batten et al., 2006; Carrington & Graham, 2001; Humphrey & Lewis, 2008; Attwood, 2007). It is echoed as a factor in withdrawing their child from school in the report by parents in Kidd and Kaczmarek's research into home-educated children with autism (2010), where nine of the ten participants reported anxiety and stress as being factors in withdrawing their child from school. McDonald and Lopes (2014) report that the parents in McDonald's 2010 study each reached a 'crisis point' which prompted them to withdraw their child.

#### Sensory issues

A contributing factor to the anxiety and stress of the children in this study (Lawrence, 2017) is their issues with sensory processing. Four of the parents report differences in sensory processing in their children (DN, SS, GE, and TE) and, although

it is not identified specifically by CY, her son Coby makes report of sensory issues in his mini-interview. These findings are in line with current research which suggests the impact of sensory processing differences in autism (for example, Bogdashina 2001, 2016; Little et al., 2015; Ausderau et al., 2014). and the active addressing of ways to decrease sensory sensitivities is identified as one of the homeschooling goals by Hurlbutt (2011).

### Language issues

Issues of both language processing and expressive language are reported by participants in this study. An element in the parents' perception of the need to intercede for their child at school includes a concern that communication by their child is not recognised by staff at the school. Participants in the study report anxiety that their children's communication (either verbal or behavioural) is missed: Elliot was unable 'to ask for help', Coby 'just literally shut down'; and Ben 'wasn't talking to anybody.' Additionally, as well as missed communication, there is concern expressed that their children's behaviour, due to the communication differences of autism, is being misunderstood by the school. Again, this echoes research into language differences in autism (for example, Attwood, 2007; Mandy & Skuse, 2008; Bercow, 2008; Jackson, 2002). Language differences as a contributing factor are more difficult to trace in the corresponding studies into children with autism who are home-educated (Hurlbutt, 2011; Kidd & Kaczmarek, 2010) and who share their education between home and the SIDE provision in western Australia (McDonald, 2010; McDonald & Lopes, 2014). However, both Kidd and Kaczmarek and McDonald and Lopes identify the failure of schools to understand the child with autism's profile, and lack of understanding by the teacher of the child's autism, as elements of the reasons for withdrawing their child from school. The challenges of the child with autism to communicate needs, desires,

emotions and anxieties are indicated in all of these studies as contributory to the parents' decision to 'step in' to their child's education.

Shared education may also offer a perceived opportunity to the parents to articulate for the child as a way of overcoming language deficits. Lamb (2009) suggests that 'for many parents of disabled children and children with SEN, good communication was often as much about the capacity of the school ... to listen to them as to talk to them (p40). Where communication between home and school is reported in this study to be good (for example, between CY, LL and Coby's school, or between SS and Edward's at-school key worker), the opportunity for increased communication both home-school and school-home is identified as beneficial by the participants.

#### ***7.2.3.2 Parents as a 'bridge' between autistic child and wider family***

There is also an awareness articulated by the participants that their autistic child does not exist in isolation within their individual family units, and in this manner the shared education can be seen as forming a bridge between the child with autism and the wider family. SS describes how sharing in her children's education is important to her as a way to enable them to interact with each other. She also explains the role that her parents, the children's grandparents, have taken as they have moved house to be nearby and support them. CY is very clear that meeting Coby's needs has an impact on his relationship with his sister, and TE describes the complexities of trying to meet the needs of her two sons, both of whom have additional, although different, needs. GE's management of Adpar takes place within the context of caring for her disabled husband and meeting the needs of her older son, who she identifies as possibly having autism (undiagnosed) also.

### ***7.2.3.3 Shared education as a 'bridge' between the parent and their child***

There is a fear articulated by the participants that their communication with their autistic children is fragile, and that full-time attendance at school may endanger its development. There is an impression that they regard themselves as the only people who fully recognise communication from their children, and that full-time attendance at school, and the resulting exhaustion and distress, may jeopardise the communication that they do share. There are issues, also, of their responsibilities in responding to their child's communication, and of not betraying their child's trust. The parents are indicating a loyalty to their children, an unwillingness to ignore what they are 'saying'. In this way, shared education is operating as a bridge between parents and child. If parent/child communication is as important to school success as the research indicates, this tenacity in maintaining the communicative link with their child becomes even more valid.

The enduring factor in this communication, as understood by the parents in this study, seems to be having the time to enable it. These parents are, at a simple level, using shared education to spend more time with their autistic children. This 1:1 time is argued as important as something that might be missed in more general, busy family life, and as something which they feel is needed to 'fill the gaps' in communication which the autism in their child are creating. There is an impression in the data of the parents wanting to fulfil their role as parents – the interacting role which happens 'naturally' in typically developing children but which has been interrupted by the communication differences of autism. The wish to support their child to communicate, to talk, to play and to have fun are all indicated in the study, as is the wish to engage in mundane matters of everyday life – washing up and cooking, walking the dog, swimming, sharing car journeys. Communication is hard-won by these parents, and

what they are describing are often huge gains which are simply not recognised as such by the wider world, despite their research-validated importance of parent/child 'discussion'.

Intrinsic to the value of many of these apparently mundane tasks, interactions and relationships is the parents' awareness of the urgency of teaching skills into adulthood. Each of the parents in this study articulated fear of the future as being a motivational factor for the sharing of their child's education. SS indicated concerns around basic life skills such as dressing and being clean, and her concern that Edward should be enabled to take his place as an accepted member of the society in which he lives. CY and TE are both very clear that learning to manage their own autism are essential skills which their children will not be helped to attain from school. DN is concerned that Ben will lose his 'foothold' in society, and GE is clear that she is intervening because of the very real fear of what will happen to Adpar if she does not do so.

#### ***7.2.3.4 Parents as a 'bridge' between their family and external agencies***

SS and CY are both keen to indicate the value of the support which they get from external agencies, SS from the 1:1 LSA who she engaged to work across the two environments of home and school, and CY the tutor she has engaged. CY is also positive about Coby's in-school support assistant, as are both DN and GE about support assistants that their child has had in the past. It seems that the parents are not 'going it alone' as an indication that they do not need help; indeed, they are all accessing support where they can, whether from the university courses that DN finds for Ben (both on-line and through his local university) or through the support and flexibility currently offered by Elliot's school. Each of the participants indicate their hope that their child may be able to access suitable at-school provision in the future. It seems they are less rejecting



school as a concept, and more indicating that the school education that is available to their child at the moment is not meeting their child's needs.

#### **7.2.4 Shared education as a way to overcome autism as a barrier to parental involvement**

This study has considered research report into the role that parental involvement plays in improving child outcomes at school. It notes that, in the literature, it is parent and child 'at home' discussion (communication) specifically which has been shown to improve educational outcome.

Autism, as discussed (6.2.4), may itself be a barrier to parental involvement in the education of the child, as suggested as valuable in research, due to reduction in 'invitation by the child' (Green et al., 2007), and reduction of 'at home discussion' (Desforges, 2003) due to the communication differences of autism. If autism is of itself presenting a barrier to communication child-to-parent and parent-to-child, the question must be asked as to whether children with autism are being further disadvantaged by this reduction in communication. Increasing parent/child communication in shared education, even when all other factors are disregarded, might in this way improve educational outcomes for these children.

##### ***7.2.4.1 This study's finding on participants' on-going communicative development with their child***

There is an impression in this study that the participants are happy to respond to the autism in their child, and to continue to be open to developing communication with their child. CY says, 'I think I learn stuff about him every day. The way his brain works – it's just fascinating to me.' SS says that 'being able to learn and explore things together has given me a better appreciation of Edward' and that she's 'always, always learning because [Edward and Eloise are] always, always changing.' Along with their own developing understanding of autism, participants give some indication in the data

that the children are also developing their own autism understanding. TE particularly is clear that the time spent sharing Elliot's education gave him access to greater understanding of himself and his needs, and through this self-understanding, increased opportunity to communicate his needs to others.

#### ***7.2.4.2 This study's findings on shared education as a way of increasing 'at home' discussion***

Central to Desforges (2003) notion of 'at home discussion' is communication that is naturally occurring between parent and child. Some of the most striking data in this study refers to the extent that opportunity for this is reduced when the child is in full-time school. DN reports that her communication with Ben reduced radically when he was in full-time school.

It was like, I could barely get him to come down for - to eat. He wasn't talking to anybody ... It was just like "no more people!" you know "people overload!"

CY reports that if Coby has had 'a really long, stressful day, he doesn't want to see [his sister]. He's not interested. He can't. There's nothing left to give.' SS recognises that it is the autism that provides the barrier to communication between her children, but is aware too that full-time school would raise its own further impediments to this occurring naturally. Edward and Eloise 'didn't notice each other, and had they been in ... two separate classes constantly ... that would just have compounded that situation.'

#### ***7.2.4.3 This study's findings on shared education as increasing time parent/child***

The data in this study suggests that shared education gives the time that is needed for communication to occur. Frequently, this non-stressful alternative-to-school time is articulated as "down time". CY says,

It's just me and him, and for him that's learning and that's down-time. It's, like, everything rolled into one: it's fun, it's play, it's learning, it's relaxing as well because there's just us there.'

However, the concept of 'at home discussion' time incorporates more than that of 'down time.' It is active, and suggests that the parent and child are actively engaged. CY does describe something of this, saying, 'You're with him, you're talking that whole time and that is an important time, really, because it's uninterrupted as well.' But there is an important caveat: Desforges describes findings that 'the more parents and children conversed with each other *about school* at home, the more the pupils achieved when in school' (this study writer's emphasis). There is plenty of evidence in this study that parents are conversing about *education* (in its widest sense), but not that they are conversing about school itself.

#### ***7.2.4.4 This study's findings on shared education giving context and potential for increased communication between home and school***

CY describes how, 'In an ideal world I'd ... go to school with him on the Monday, and then have him [at home] on the Tuesday ... [so that] I'd know [what he was doing in school].' This is echoed in TE's frustration that she did not know that Elliot was struggling: '[The school] had not really fed back at all.'

There is suggestion in this study, therefore, that parents would welcome improved communication between school and home and that this could in itself help support communication between child and parent and 'scaffold' at home discussion about school. Improved understanding of context, coupled with more time and access to the (happier) child could facilitate increase in the 'at home discussion' seen as so beneficial in the literature (Desforges, 2003). In answer to the question, 'Can education shared between home and school benefit the child with autism?', this gives an element

of 'benefit' which is more than a reduction of elements which impact negatively on the child because of autism, or the increase of elements which impact positively on the child because of autism. In this case, shared education may enable the child with autism to access the benefit described in the literature which increased communication between parent and child affords all children.

#### ***7.2.4.5 Parental insecurity in their role as educators***

There is some indication in the data from this study that participants' self-perception of their role as educators lacks confidence. CY says that she could not take on Coby's full-time education, SS needs the LSA's help in managing Edward's behaviour, GE admits to being made unhappy by the situation she finds herself in. This lack of self-confidence contrasts sharply with the energy, tenacity and commitment which they describe as bringing to the role.

Their insecurity may be fuelled by awareness of the power imbalance of their position. GE's intervention in Adpar's education is the only way that the school is willing to allow him to attend school at all (which is unlawful, although GE has not challenged this). She is doubly frustrated as she believes that to force the school to allow her son to attend more – even if she could do so – would further jeopardise his education as the school claims to be unable to include Adpar in learning activities with his peers and is merely holding him 'in a room on his own with his 1:1.' In contrast, CY is well aware of her tenuous legal position, and is consequently nervous of asking for more at-home time as she feels that the school is very reluctant to continue even with what she has negotiated. DN is frustrated that Ben cannot access education without the experience making him ill; TE has accepted that the school that Elliot has moved up to would not consider shared education, and to ask for it too strongly would jeopardise the support that he is being offered within school. The parents in this study

are in many ways marginalised, and perceive that the balance of power between them and the school to be unfairly balanced. In her research study, Arora notes the 'big power differential between the family and the school' which is an intrinsic challenge to shared education, arguing for the need for 'a genuine spirit of partnership between the school and the family involved [where] both parties [are] willing to compromise and to respect each other' (Arora, 2006, p. 63).

#### ***7.2.4.6 Parental confidence in their role as parents***

There is, however, considerable indication in the data that participants are finding the additional time provided by the at-home element of shared education fulfilling for their role as parents, and that they are confident that the shared education which they are providing is a better 'fit' (McDonald & Lopes, 2014) for their children. They describe this element very much in terms of 'happiness' – of their child, of themselves and of the wider family. Although there is frequent indication in both this study, and in the similar studies explored, that the parents' intervention is out of fear of what will happen if they do not intervene, there remain many indications that parents feel empowered and that they believe that they have 'found a ... plan that works' (Hurlbutt, 2011, p. 247). Important to this is the richness of their shared experience. Positive elements able to be enjoyed by parent and autistic child together include, in this study, reading together, cooking, shopping, telling stories, going for walks together, spending time as a wider family and enhancing sibling and cross-generational interactions. This element of a rich experience is articulated in Kidd and Kaczmarek's research as an increase in 'well-being', described under their second theme, that of the experience of 'coming home' (Kidd & Kaczmarek, 2010, p. 265). McDonald (2010) similarly describes at-home elements of value in the shared model as including cooking, washing, housework and caring for a pet, as well as social undertakings such as visiting

the library and shopping. These 'life skills', as well as being intrinsically useful for the child to master, suggest that the additional at-home time is enabling an increase in both the quantity and quality of the child's interaction with parents and with wider family.

Finally, there is suggestion in the data that the parents in this study experience positive self-perception through their adoption of the role of shared educators. There is indication of pride in their role as 'protector' of their child, and as the person who has responded to their child's need and justified their child's faith in them. This may be overt, as in CY's awareness that Coby 'knows what I went through to get him these Wednesdays' or more hidden, as in SS's assertion that she has worked hard that both her children be 'happy'. Despite limitations and frustrations, there is a strong impression in the data for this study that these parents understand that they are 'doing their best'.

### **7.3 SUMMARY**

Parents in this study indicate their belief that in sharing in his or her education, they are meeting a need in their child. There is also indication that the shared education may be meeting the need to help their child felt by the parents. They are each clear that they are protecting their child in reaction to their awareness of their child's distress, distress which they feel is not always understood by others due to the communication differences of autism. They feel confident that they know and understand their own child, and report awareness of their child's autism which may exceed, and which may predate, professional concern.

In sharing their child's education, they see themselves as responding to their child's lack of learning at school, either academically or in learning what is needed to progress in society and as adults. In addressing these needs, they are keen that their

child's autism needs be recognised and respected, rather than seen as something to be hidden or 'repaired'.

Each of the participants is working hard to maintain access to school for their child, for both its academic and social input, and they express frustration when the work that they do to help their child results in the school perceiving that their child has reduced needs.

The parents in this study see shared education as more than just 'not full-time school' or 'not full-time home'. They see it as a way of facilitating communication and consistency across the different elements of their child's life, as reacting to their child's changing needs and as a way of positively impacting on the autistic child's place within the wider family. They perceive that the time and commitment which they bring to the shared education has a positive impact on their own relationship with their child, overcoming the more isolating elements of autism's communication difficulties, and enabling their relationship with their child to be nourished and to grow. As such they may be unconsciously identifying the importance of the parent/child relationship as indicated in research.

Parents in this study are indicating acceptance of their child's autism, but not of the limitations which external agencies impose on their child because of that autism. They are indicating that a way to overcome these limitations would be if they could better understand the context of their child's at-school time, and be enabled by the school to help their child to better access that time through stronger communicative links school/home, and specifically through greater willingness for schools to listen. Although there is evidence of self-pride in what they are doing to support their child,

there is also indication of feelings of vulnerability and an awareness of the imbalance of 'power' between school and home.



## **8 CHAPTER EIGHT: CONCLUSIONS AND IMPLICATIONS**

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### **8.1 CONCLUSIONS FROM FINDINGS**

Data from this study suggests that the researcher's original theoretical postulate, articulated in nine theoretical propositions, as to the benefits to the child with autism of shared education is broadly perceived also by the participants in this study. There is suggestion that the participants share the perception that sharing education between home and school can address issues of sensory and language differences in their children, and that they see it as a time of self-repair needed by their children due to the anxiety engendered by the pace and pressures of school. The data suggests that participants wish to maintain access for their child to the school's academic curriculum and are endeavouring to support that access from home, but that they also want to enable their child to have the individualised curriculum which they believe he or she needs. It suggests a wish in parents for schools to see their children as individual, rather than in terms of a set of predetermined criteria, and to accept their child for who he or she is. There is some indication that they value their child's continued access to the social interactions of school, and would like them to continue to have this if the child can be supported in it. Parents in this study report that sharing education for their child with school is giving them increased communication opportunity with their child and that they feel that sharing education is making their child – and their whole family – happier.

There is no suggestion in this data that the participants believe that sharing education is relieving bullying, as none report this to be an issue for their child.

There is broad agreement between the experiences of parents home-educating their children with autism as reported in similar studies and the experiences of parents

sharing the education of their children with autism as reported in this study. These studies report broadly similar motives for the withdrawal of their children from school, and broadly corresponding goals that are hoped to be achieved by this withdrawal. What is not clear in the research by Kidd and Kaczmarek, and Hurlbutt, is whether the parents in their studies would have retained a shared education with the school had this been available, although there is some evidence that at least in some cases they might have done so. Indeed, there is a single report in the study into home-education for children with SEN by Parsons and Lewis (2010) of a family who identify a drawback of elective home-education as being 'lack of a social group, hence the one day a week back into school' (p. 77). These small suggestions may hint at a wider wish in parents home-educating their children with SEN to maintain a school-based element if it were to be available.

There is some suggestion in the data from this study that parents are using shared education to facilitate or enhance communication with their autistic children. This may bring benefit as they fulfil their general responsibility as parents (rather than as parents of autistic children) to support their child through 'at home discussion' (Desforges, 2003). The increased time that parents and children have together in shared education may help to minimise the barriers to this discussion caused by the autistic child's communication differences, and by the exhaustion reported by parents in this study experienced by their children with autism after full-time days at school.

The data in this study suggests, therefore, that sharing education between home and school can benefit the children with autism, where benefit is taken to be the reduction of elements which impact negatively on the child, and the increase of elements which impact positively on the child, as perceived by the parent.

## **8.2 IMPLICATIONS FOR POLICY AND PRACTICE AND SUGGESTIONS FOR FURTHER WORK**

There are a number of implications for policy and practice in the education of children with autism which emerge from the findings of this study, and a number of areas which merit further investigation in a future study.

### **8.2.1 Including parents as key educators of their autistic children**

The considerable body of research regarding the value of including parents in decision-making regarding the education of their autistic children has already been described in this study. Most of this, although entirely pertinent, appertains to the benefit of including parents in the content and delivery of the ‘at school’ element of this education. Initiatives such as the Structured Conversations approach developed by the DCSF 2009 Achievement for All project exist to provide scaffolds for successful parent/school communication. The findings of this study, however, together with the cited studies by Kidd and Kaczmarek (2010), Hurlbutt (2011) and McDonald and Lopes (2014), together with Parsons and Lewis (2010) and Arora (2006) suggest that recommendations regarding parental involvement in school education (for example, Badman (2009); Lamb (2009)) continue to fall short in autism education as it exists ‘on the ground’ in many cases. What has been less the subject of research to date is that into ways of supporting parents as key – and continuing – educators of their autistic children in the ‘at home’ element of the child’s education. This ‘at home’ element is important, as recognised in the literature whether that child’s education is formally shared between home and school through a shared education or flexi-schooling model, or shared intrinsically through the more usual practice of school attendance five days a week for 39 weeks of the year. The extent to which autism may provide an inherent barrier to this element, and therefore requires that child and parent access additional time and/or support, merits further study.

### **8.2.2 Providing individualised responses to the autistic child's needs**

Findings by McDonald and Lopes (2014) suggest that flexible, individually tailored and respectful input into autistic children's schooling can be valued by parents even when the actual hours given to this input are few. This study supports these findings, and those suggested by Arora (2006) and further suggested by Kidd and Kaczmarek (2010) and Hurlbutt (2011), in suggesting that parents of autistic children may value support given by schools, or school agencies, even when they have chosen to withdraw their child from school. The element of providing a break or respite for the parent educator in this circumstance is dependent on the at-school element meeting the needs of the child and providing an education which is suitable, accessible and comfortable for that child (McDonald & Lopes, 2014).

### **8.2.3 Understanding where parents are responding from 'need'**

Findings from this study supports various research reports (for example, Arora, 2006; Parsons and Lewis, 2010; Badman, 2009) in suggesting that some parents who intervene in their autistic child's education do so because they perceive that they have no alternative. Intervention by parents in their child's education, whether this be full-time through elective home-education or part-time through a process of shared education, which takes place because of a perceived lack of alternative should be viewed differently from that which occurs because of parental choice or philosophy (Badman, 2009). Where parents who elect to educate their children at home for ideological or philosophical reasons may defend their right to non-intervention by education authorities, this should not exclude those who would welcome support from school or other education providers from accessing it (Arora, 2006). McDonald and Lopes' report on parents who are home-educating with the support of SIDE in Western Australia suggests a model of educational support which could usefully be considered by such parents. Furthermore, Schafer and Khan's report (2016) into home-educating

families in America highlights the extent to which shared education between home and school already exists in many parts of the United States, and the extent to which ‘flexi-schooling might be a viable option’, especially where the child has a disability (Schafer & Khan, 2016, p. 5).

#### **8.2.4 Enabling both ‘at school’ and ‘at home’ elements**

What constitutes an education which is efficient, full-time and suitable to a child with autism’s age, ability and aptitude, and to his autistic needs, as required in English law (Education Act, 1996, section 7), remains open to interpretation. However, research suggests that parental input may provide a valuable element. Findings from this study suggest that this element may be used to support the child’s education through direct adult input, delivered during the child’s ‘at home’ time, and also that it could support the child to better manage school, and the school to better understand and accommodate the child, if facilitated by improved communication.

#### **8.2.5 Recognising the value of communication**

Intrinsic to the recognition of the value of parents as communicators is that of their value as communicators on behalf of their child. The ‘voice’ of autistic children can be difficult to hear in discussions on the most suitable provision for their education (Lewis, 2010), although Harrington highlights that students with autism ‘are aware of their learning needs and preferences and can articulate these ... if given the opportunity and the right supports to enable them to do so’ (Harrington, 2014, p. 213). Participants’ perception of themselves as a ‘voice’ to explain and intercede for their child is one which emerges strongly from this study. The value felt by the parent as being someone able to recognise communication by their child with autism, and to ‘translate’ for that child to school (and to ‘translate’ school for the child) is evident in findings in this study. As communication difficulties are inherent in autism

identification (DSM – 5, 2013), support with communication both by and with the autistic pupil remains an important role for parents.

#### **8.2.6 Considering shared education as a defence against social isolation and bullying**

Although over 40% of people with autism are reported as having been bullied at school, and although 59% of parents of children with 'high functioning' autism or Asperger syndrome in the NAS survey said that their child had been bullied (Batten, 2006), in the experience of the researcher of this study, bullying was not something that her son experienced during his (shared) education. Nor, although it was reported to be a motive for parental intervention in each of the other three studies explored in depth in this research (Kidd & Kaczmarek, 2010; Hurlbutt, 2011; McDonald & Lopes, 2014), it was not reported to be perceived to be an issue for children of the participants in this study (Lawrence, 2017).

One explanation for the finding in this study (Lawrence, 2017) may be that the sharing of education is itself alleviating the potential for bullying, perhaps by building confidence, perhaps by allowing the pupil more perceived autonomy, or perhaps by allowing the pupil an 'out'. According to Blood and Blood (2004), 'Students with low self-esteem and poor confidence in their communicative competence were more likely to be victimised by bullies' (p. 69). They add that, 'Research reports from interviews of bullies about their "targets" suggest that they mark students who are perceived as cautious, anxious, quiet, passive, withdrawn, unassertive, insecure, and unhappy' (p. 69). It may be that the increased happiness and decreased anxiety levels reported in this study may be acting as a protective factor against bullying. Olweus (2003) rejects the idea that empirical research suggests that self-esteem and insecurity are factors in becoming a victim of bullying, but suggests instead that personality characteristics or

typical reaction patterns are key factors in the origins of bullying problems. Whilst the children in this study have not altered their personality characteristics (which, given the prevalence of bullying in autism may be autistic features), it is possible that their reaction patterns may be altered. This element of shared education, as a potential shield against bullying, warrants further investigation in a future study.

#### **8.2.7 Being sensitive to the needs and vulnerabilities of these parents**

As identified in this study, these parents felt that their autistic child's needs were not being met in school, and so they have felt compelled to withdraw their children from part of their schooling in order to meet those needs. This is “flexibility” provided by them as parents, and there is much in it as recorded in this study that can be understood as successful and beneficial. However, it may also come at a price. As the researcher in this study writes (Lawrence, 2012, p 137):

But is it fair? Parents are desperate to do what is best for their children, and may be willing to give up their own careers and aspirations, to vastly reduce their incomes and to work in isolation and often facing suspicion and ridicule, in order to do what they can to help make their child's life better. Is it fair to expect them to do this, and in this way to take on this lion's share of responsibility for their child's learning and development?

The parents in this study are providing part of their child's education because, as noted by Parsons and Lewis, it is for them and their family 'the only way.' Their understanding of the strain felt by their children, and their perception of the limits brought to their children's future success, have been clearly articulated by the participants in this study. What they have not expressed in this study is the tremendous strain that this is putting on their own physical, mental, emotional and financial health. This is articulated more clearly in the studies by Hurlbutt, and Kidd and Kaczmarek. Hurlbutt reports that 'a number of the parents addressed concerns they had about stress

and that commitment of both parents is needed to successfully homeschool their children' (p. 248), and Kidd and Kaczmarek quote one mother as reporting, 'It's hard for me because I don't want to be at home' and another as regretting how, if she had not had to withdraw her child from school, she 'could have had a life and had a job, or completed my studies.'

The participants in this study are not complaining. For many, their insecurity in their legal right to share education tends to lead to feelings of gratitude that they are being 'allowed' to do so. SS describes herself as being in a 'fortunate position', DN describes herself as 'highly, highly privileged' and CY describes how she will be '100% campaigning to continue [to be] allowed' to share Coby's education. However, these parents are vulnerable. One of them posted on Facebook (on an open post, not as part of this study):

"I can't do this anymore. I can't carry on like this anymore. I wish I'd been the one who died 6 years ago, because then the boys wouldn't have been put through any of this. I just don't know what to do anymore." (26/5/16)

The evident distress of this post suggests that it is not just the mental health and well-being of the children in this study which requires urgent further study, consideration and support, but that of the parent participants as well.

### **8.3 LIMITATIONS OF THE STUDY**

#### **8.3.1 Restricted perspective**

The focus of this study is on parents' construction of the motivation for, and experience and perceptions of, shared education with their children, and of their understanding of its benefits. The decision to focus on parents as the participants in this study occurred not least through practical consideration: shared education is not a legal



right in the UK as is the right to a full-time education that takes place in school or to a full-time education which takes place 'otherwise', which is usually taken to mean through elective home-education. Shared education, whilst legal if at the instigation of the parents, is permitted entirely at the discretion of individual head teachers, who 'can refuse if you want to send your child to school some of the time' ([www.gov.uk/home-education](http://www.gov.uk/home-education) accessed 12/11/16). Both participants and researcher were aware of the danger of 'rocking the boat' of these children's current provision. The parents acted as gatekeepers through which the research had access, and respect for their wishes as to who else, if anyone, should be approached was paramount. This resulted that, although access to schools was requested, it was not granted by the parents in four of the case and was rejected by the school in the fifth.

The decision to use parents as the participants in this study resulted also that 'voice' of the child is largely absent. Again, the parents acted as gatekeepers in the study with no direct approach being made to the children, although in two cases the parents decided to enable an indirect response from their child through an informal interview conducted by themselves and forwarded to the researcher. The parents in all cases were keen to articulate how they felt that they reflected the 'voice' of their child, and these enabled responses are therefore included in this study as an extension of the parents' own. The United Nations Convention on the Rights of the Child (UNCRC, Article 12, 1989) encourages adults to listen to the opinions of children and involve them in decisions about matters that relate to them. It has two key elements – the right of the child to express a view and the right to have that view given due weight. However, finding a way to enable children to express their view is complex. Hill (2006) examines priorities regarding taking part in research as expressed by children and young people. These include 'a sense of benefit ... a choice about how to communicate,

flexibility about ... level[s] of involvement, clarity ..., diversity, comfort and – if possible – fun' (Hill, 2006, p. 85). Whilst research suggests that many children welcome the possibility to be 'heard' in research (Grover, 2004), Lewis (2010) highlights that such research may tend to be positively biased, since it is children who are supportive of consultation who are most likely to be the very children who would volunteer to take part in such research. She cautions also against the danger of over-simplistic or token involvement of children. Citing Beresford, Rabiee and Sloper (2007) and Lewis, Robertson and Parsons (2005), she identifies that the researcher must be aware of the 'painstaking and time-consuming underlying requirements' (Lewis, 2010, p. 16) that are needed to support the authentic involvement of the child's voice in research, particularly when the child in question has a disability or special needs.

In line with Lewis' recommendations, this study is 'explicit and transparent' about what is feasible concerning the inclusion in it of the child's voice (Lewis, 2010, p. 16). The focus of the study is rather the parents' perspective and sense-making regarding shared education with their autistic child, and, whilst it recognises the parents' wish to speak for their children and to act as their 'voice', its concern is with them as participants.

### **8.3.2 Methodological limitations**

As an 'insider' or 'complete-member' researcher as discussed (3.2), the researcher on this study was able to bring personal perspective to both the study design and to the analysis of the data gathered. Leech (2002) suggests that, 'what you already know is as important as what you want to know' (p.665), in that previous knowledge shapes the way that a researcher approaches finding out about a subject. The researcher in this study had shared the lived experience of sharing the education of her autistic son

between home and various school settings throughout the twelve years which preceded this study.

The strength of this position, in addition to the understanding and perspective which it brought to the study design, was the experiential connection which it afforded with the participants. Interpretative phenomenological analysis (IPA) is 'preoccupied with the quality of experience' (Pietkiewicz & Smith, 2014, p. 7), and the researcher's ability to access that quality of experience was, arguably, enhanced by her position as someone sharing that experience. Where the participants were trying to make sense of the phenomenon of sharing education with their autistic child, the researcher's shared perspective was an asset in 'trying to make sense of the participants trying to make sense' of that phenomenon (Smith & Osborn, 2007, p. 53).

Conversely, though, the researcher's very familiarity with the subject led to methodological tensions. Where IPA seeks access to a participant's personal world, this access may be complicated by the researcher's own perspectives. Phenomenology aims to set aside assumptions and to describe the phenomenon under study in its purest form through 'bracketing out' preconceived ideas (Moran, 2002). The two-stage interpretation of the double hermeneutic indicated above involves that, as the researcher used her own perspective to try to understand shared education from the viewpoint of each participant, her perspective could not be removed from that understanding.

Pietkiewicz and Smith (2014) recommend that 'both participants' and researchers' interpretation of phenomena is taken into account in the process of analysis (p. 7), allowing that the researcher's non-neutral stance can be fully explored in the meaning-making of the data. Indeed, McConnell-Henry et al. (2009) assert that the concept of 'bracketing out' as understood in descriptive phenomenology is not

necessary in IPA as the ‘researcher is part of the research; in the world of the participant, the researcher's previous understanding and knowledge ... helps interpretation’ (Tuohy et al., 2013).

The researcher’s pre-structural knowledge has been articulated in this study by following Yin’s advice (2013) to develop elements of theory early in the design process and before collection of data, in order to help frame the study. This theoretical postulate resulted in the nine propositions which informed both data gathering and data analysis. These provided scaffolding for the articulation of the researcher’s understanding of shared education within a literature-based and auto-ethnographical framework, contextualised the interviews and were intrinsic to the study’s design.

However, the use of theoretical propositions created epistemological questions as to how they affected both data collection and data analysis. IPA as a methodology emphasises the importance of openness and the need to avoid theory-driven questioning. The very existence of propositions about shared education was, to an extent, ‘in danger of presenting an obstacle to interpretation’ (Smith, Flowers & Larkin, 2009, p. 25), and provided a tension to both analysis of data and to the consideration of the best way of presenting and discussing findings.

The researcher resolved this tension by analysing the data with reference to the propositions separately from the main body of the research. This, as suggested by Finlay (2008), enabled her insider understanding as a parent sharing education with an autistic child to be brought to the fore and to be recognised for its influence and bias (Tuohy, 2013).

This analysis was then both presented and discussed as a discrete section within the study. Reframing the data in this way provided the researcher with the opportunity

to scrutinise each case study with reference to the specifics of the propositions, the propositions providing the lens through which initially to approach the data.

### **8.3.3 Summary**

The question considered in this study is: Can sharing education between home and school benefit the child with autism? The use of an interpretative phenomenological analysis approach which explores the lived experience of five mothers sharing the education of their autistic child between home and school enabled the gathering of rich data, able to be considered and explored in a variety of ways. The findings from this yield an original contribution to knowledge as no previous research has been undertaken into this phenomenon. This contribution includes an indication of the parents' motivation for sharing education, their rational expositions of the benefits of that shared education as they perceive it in the case of their individual child, and something of the emotional intensity brought to their experience of that shared education. It is a small study, undertaken by a single researcher, and in line with IPA philosophy, makes no claims to generalisability or transferability. What is implicit in the study, though, are the twin questions of how valuable it would be to other parents of autistic children who perceive their child to be distressed by school to present them with an option of extra time with that child at home, and how valuable it would be to parents who have felt the need to withdraw their autistic child from school, to present them with an option of some tailored and supportive time at school. These questions remain to be answered in future studies.

[71, 074 words]

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## 10 APPENDICES

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*Appendix 1: Shared education information sheet*

ClareLawrence101@gmail.com

www.clarelawrenceautism.com

### **Shared Education and Autism Research Study**

#### **Research question: Can sharing education between home and school benefit the child with autism?**

Thank you for your interest in this research study. The study is for parents/carers who have a child with a diagnosed autistic spectrum condition who are sharing that child's education between home and school (flexi-schooling).

#### **Who is the researcher?**

The research is being carried out by me, Clare Lawrence, as part of my PhD doctoral thesis at Sheffield Hallam University. I am a teacher and a parent of a child with autism who has shared his education between home and school throughout both primary and secondary stages. I am interested now in finding out about the experiences and perceptions of other parents and school professionals who have explored this model as an educational provision for children with autism spectrum conditions.

#### **What will I be asked to do?**

If you decide you would like to be considered for this study you will need to sign and return further information and consent forms, available on my website or from me at the email address below. If you are chosen for further involvement I will contact you to arrange a time and place to meet you to complete the initial interview. I am happy to travel to your home for this, or to meet at another location if you prefer. The initial interview will take approximately one hour and will be recorded, so that it can be transcribed for further analysis. You will be asked about your experience of school/home shared education with your child, and your thoughts and opinions about it. You will be free to choose not to answer any questions should you prefer, and to withdraw from the interview at any time if you wish.

Following this initial interview we may discuss further data gathering techniques we could use, with your approval, to form a fuller picture of your shared education. These might include, for example, keeping a journal of activities for the week, sharing drawings or writing by your child, or talking to your child's school. However, these will

only happen with your approval and consent, and you need not take part in any further data gathering if you prefer not to.

**Will I have to tell my child's school that I am taking part in this study?**

No. You do not have to tell your child's school you are taking part in this research if you would rather not, and you will not be asked to give details of which school your child attends as part of this study.

However, if you are happy for your child's school to be approached about this study, this will only happen in ways agreed by you, with your full knowledge and consent.

**Is the research confidential?**

All responses to this study will be strictly confidential. Only I (and my supervisors) will have access to your original responses, which will be anonymised. You and your child will be given a pseudonym – you may choose these if you wish - and any identifiable information about you or your child's school will be removed in my published thesis and in any related materials. All data collected throughout this study will be stored securely, and consent forms will be stored separately from interview recordings, transcripts and notes, in order that no direct connection can be made. Additional permission will be sought from you to use any visual data such as drawings or photographs, and these too will be anonymised.

**How do I know that this study is being conducted properly?**

Approval for this research study has been granted by the Ethics Committee at Sheffield Hallam University.

**What if I decide not to take part in this study?**

This study is completely voluntary and it is your choice completely whether or not to take part. You are free to take part in some parts and not others, and to withdraw from the study at any time.

**What if I have further questions about this study or if I want to complain about any aspect of it?**

Further information about this study is available through the contact details given below. Any concerns or complaints about this study or about my conduct can be made to my supervisors, or to the Chair of the Faculty Ethics committee at Sheffield Hallam University.

**What will happen to the information collected in this study?**

Findings from this research will be published in my Doctoral thesis. It is also anticipated that, both during research and after completion, papers will be submitted to

relevant journals and findings further shared through talks, conferences, wider publications and interest groups. All findings from this research will be anonymised at all times.

### **Feedback from this study**

If you take part in this research you will receive a summary of findings at the end of the study period. This is anticipated to be between two and six years from the time of your participation.

**If you wish to be considered for this study, please email me at**  
**[ClareLawrence101@gmail.com](mailto:ClareLawrence101@gmail.com)**

Thank you,

*Clare Lawrence*

Clare Lawrence

**Supervisors: Dr Luke Beardon** L.Beardon@shu.ac.uk

**Dr Anne Kellock** A.Kellock@shu.ac.uk



## **Shared Education and Autism Research Study**

### **Participant Information and Consent Form**

Thank you for your interest in participating in the above research study.

Please complete this further information sheet to give me some details of your shared education experience. Both it and the consent form may be signed and returned to me electronically (I will ask you to hand sign a copy of the consent form at the beginning of the research if you are chosen to take part).

Initial numbers of participants in this study will be fairly small, so please understand if I am not able to include you at this stage. However, I may be looking for further participants at a later stage in the study, so I would be grateful if you could indicate on the form whether you are happy for me to keep your details on file.

Thank you again for your interest in this research.

Clare Lawrence

ClareLawrence101@gmail.com

[www.clarelawrenceautism.com](http://www.clarelawrenceautism.com)

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### **Potential Research Participant Further Information**

1. Does your child have an autism spectrum diagnosis? **Yes/No**
2. Does your child attend a mainstream school for some parts of the school week and spend the remainder of his/her education at home/with you? **Yes/No**

If 'yes', please give a rough indication of the proportion of your child's education that takes place in each setting (e.g. 60% / 40%) **School** \_\_\_\_ **Home** \_\_\_\_

3. During the 'home' part of your child's education, are you following any specific autism programmes? **Yes/No**

If 'yes', please indicate which one(s)

4. How old is your child?

5. Where are you located? (e.g. Wales, East Midlands etc.)

6. May I keep your contact details for potential participation in the study at a later stage? **Yes/No**

## **Shared Education and Autism Research Study**

### **Consent Form**

*Please answer the following questions by circling your response.*

Have you read and understood the information sheet about this study?

**Yes / No**

Have you been able to ask questions about this study if desired?

**Yes / No**

Have you received enough information about this study?

**Yes / No**

Do you understand that you can withdraw from this study

- at any time?

**Yes / No**

- without giving a reason?

**Yes / No**

Your responses will be anonymised before they are analysed. Do you give permission for members of the research team to have access to your anonymised responses?

**Yes / No**

Do you give permission for your anonymised responses to be included in publications in relation to this research?

**Yes / No**

Do you agree to take part in this study?

**Yes / No**

Signature of participant: \_\_\_\_\_ Date: \_\_\_\_\_

Name (block letters): \_\_\_\_\_

Email: \_\_\_\_\_

*Please return to [ClareLawrence101@gmail.com](mailto:ClareLawrence101@gmail.com)*

**Thank you**

*Appendix 3: Example of coding*

Code 1: Lack of confidence in school/doctors

Code 2: Knowledge of own son

Code 3: Overwhelmed by situation

Code 4: Evidence of support from school/.doctors

Code 5: Self-awareness

*Ok, so this 1:1's new is she?*

She - because the Juniors a different school so it didn't continue with his old 1:1 - she's new to Adpar

*This year?*

Yeah and I don't think she's very good to be honest.

**No, I hate her.**

The thing is, he - we - we set out things. Adpar will say things that you just have to ignore because if you didn't you'd get home and you'd just cry. I mean, as his mum, you know, he tells me to go and kill myself and, you know, and all sorts and I explained this to the 1:1 and I said, "He will come out with things and he will say them."

**And then she cried when I said "I'm going to gouge your eyes out."**

And then she cried when he said he was going to gouge her eyes out with a pencil

**And also she lied by saying that I threw a cupcake at her and she cried.**

**Yeah.**

*How much - has she had training?*

As far as I know, yeah, so, that's what I don't really understand. I don't think they understand the whole... Because I think they've dealt with children with ADHD but I don't think they've dealt with children that have got sort of every - everything, you know and with Adpar it's very much a case of it's ASD and ADHD and possible PDA which is kind of like...

**Which the doctor doesn't believe is actually real.**

**Exactly**

**Because he's an idiot.**

*But PDA's under ASD anyway?*

Yeah, exactly, yeah. And Social Anxiety Disorder, so it's all a bit mixed and I suppose, if you have one child with that and one child with that, it's okay but, when it's the same child with everything just, you know. And I mean, as his mum, I still learn things every day because, you know. Today we had to have pancakes for lunch because, you know, there was nothing in the house that he likes and, you know...

*Nothing wrong with pancakes!*

Exactly [laughs]

*So, the - when he was still in the infants, was he actually going into the classroom then?*

He did for a while but they had a special room where, if Adpar felt anxious, he could just go straight to that room which he chose to do more often than not and then they managed to - at the beginning of Year Two - to get him to sit and do quizzes so they could determine how far on he'd got but, without any actual education at school, he still managed to do quite well in his quizzes, so.

*So he's learning - so where is he learning, then?*

Well, I think he learns at home. His brother in is top 5% of Britain for his IQ

**And so am I.**

Yeah, he's been assessed to be in the top 10% and, I mean, we just do things at home, you know. We'll be walking along and we'll see a building that's different so we'll look it up and find out about it so - but, I'm that sort of person...

**That's never happened.**

[laughs]... When I'm with my children, we just do things anyway like pumpkin carving, you know.

*So, are you doing formal lessons?*

**Shut up! Because I can't concentrate!**

Okay, just calm. Breathe.

**No! I can't concentrate.**

Okay. Yeah, I do more at home. We'll do a bit of English and a bit of Science or a bit of Maths.

**Shut up!**

Okay. Adpar, you might have to stop for a bit.

**No! No! I'm not stopping!**

Well, I need to talk, okay?

**No. No you don't.**

Yeah, so, we'll do more formal things at home and I lesson plan as well, so.

*So, are you getting help from the school to do that? To keep on the same curriculum?*

No

*No? It's just you doing it?*

It's just me doing it because I don't want him to not have a job when he comes to work, you know, so.

*So, have you had training?*

I used to teach in schools. I taught IT in Primary School, so. I've got a degree in Childhood and Youth Studies, so I'm from that kind of background.

*So you can do all that stuff?*

Yeah.

[Pause.] *No problem. Brilliant. So you're doing sort of formal English, formal Numeracy, obviously some formal IT as well, probably?*

Yeah, yeah that sort of thing.

*A bit of Science?*

Yeah. Yeah, Science mainly from workbooks and then we've got a 'Grow-Your-Own-Christmas-Tree' thing with those crystals. So we do bits like that and then we do why it worked and what's in the packet and things like that.

*Brilliant. Okay. If the school were able to give you help, with resources and information, would that help you?*

[Laughs] Probably not, if I'm honest.

**Can you shut up...**

I think I know a lot more about my child, you see...

**Can you shut up...**

...because I know what works.

**Because they're idiots!**

Yeah

**And I hope they die! Forever!**

Okay, yeah...

**Then I needn't go to school.**

...so, you know.

**Themes:**

1. **Code 1 – GG has a lack of confidence in both the school and medical systems to either understand or support Adpar.**

GG is frustrated that the school do not seem to understand Adpar 's needs and that it seems unwilling to listen to advice. She worries that he is not learning during his time at school and doesn't believe that the school sees Adpar's learning as a priority.

GG states her opinion that the new 1:1 teaching assistant who works with Adpar is not very good. She seems frustrated that the school did not fully appreciate what she was telling them about the remarks that Adpar makes, and seems to



feel that the school is not equipped to understand Adpar's condition, which is complex. She quotes names of conditions, but seems to have received little support in understanding or addressing these, and Adpar's comment that the doctors do not consider one of his possible diagnoses to be 'actually real' suggests that she and the medical team around Adpar are not in full agreement. When suggestion is made of the possibility of more help with academic input from the school, GG gives the opinion that she would be unlikely to accept it, as she feels she knows more about Adpar than the school does, and that through her full-time acceptance of him and time spent with him, knows 'what works.'

## **2. Code 2 - GG feels that she knows her own son and understands his needs.**

GG feels that she understands and accept Adpar and she uses their time together to try to build strategies into the future.

GG understands that Adpar will say things that are challenging, and manages this behaviour through ignoring them and not 'rising'. This is a deliberate policy, and there are examples of its use throughout the interview. She uses some calming tactics during the course of the interview, and indeed Adpar's behaviour (apart from the content of his comments) is good throughout the interview. GG's non-confrontational approach seems to work as an immediate tactic, although arguably it is not fully addressing the issue. She acknowledges that she is still learning about Adpar and that, although she knows him 'best', she still has more to learn.

## **3. Code 3 – GG finds the situation stressful.**

Code 3: the school's reliance on GG to share Adpar 's education is causing strain.

GG acknowledges that if she had not developed the strategy of ignoring the content of much of what Adpar says, she would be distressed by it ("If you didn't [ignore it], you'd get home and you'd just cry.") She gives the example of having to make pancakes for lunch because there was nothing else in the house that Adpar would eat at that time, and some of her responses to questions about his education lack conviction or confidence. She identifies that she is not sharing Adpar's education by choice, but from necessity, because "I don't want him not to have a job when he comes to work."

4. **Code 4 – GG understands why Adpar's behaviour is a challenge to the school and is able to acknowledge some support given by professionals.**

Code 4: GG understands why Adpar 's behaviour is challenging for the school

GG knows that Adpar's comments are unacceptable. She acknowledges that the school had previously provided a room for Adpar to use when he became anxious, and reports on the quizzes used by the school for assessment. Her statement that her other son is “in the top 5% of Britain for his IQ” shows that she has had, and has accepted, assessments from professionals, and her recognition that Adpar is “in the top 10%” shows this further. Her listing of possible diagnoses for Adpar further shows acceptance of professional input.

5. **Code 5 – GG is aware of her situation and of how difficult and challenging it is**

Code 5: GG is self-aware

GG shows awareness that Adpar's behaviour is challenging and that the school approach to it is not ‘working’. She shows acceptance of her son and that she is trying to find ways of managing, but her use of the repeated ‘so’ and ‘you know’ suggest elements of hopelessness and powerlessness.

[.../]

**“I don’t think they understand”**

CL: frustrated that the school does not fully appreciate what she was telling them about the remarks that ES makes

LG: Mother not really engaged with school; passive

**“ASD and ADHD and possible PDA ... Social Anxiety Disorder” ... “Which the doctor doesn’t believe is actually real” ... “Exactly”.**

CL: quotes names of conditions, but seems to have received little support in understanding or addressing these, and Adpar's comment that the doctors do not consider one of his possible diagnoses to be 'actually real' suggests that she and the medical team around Adpar is not in full agreement; Adpar aware of discussions around his behaviour, and repeating comments made

LG: Parent continues to take the lead from child. He is saying what she would like to say

**“Because he’s an idiot.”**

CL: No response from GE

LG: Child says directly what mother seems to feel passively

**“Today we had to have pancakes for lunch because, you know, there was nothing in the house that he likes.”**

CL: gives the example of pancakes for lunch because there was nothing else in the house that Adpar would eat; Apologetic? Overwhelmed?

LG: Apologetic for both school and herself

**“They had a special room where, if Adpar felt anxious, he could just go straight to that room ... at the beginning of Year Two [they got] him to sit and do quizzes so they could determine how far on he’d got ... Without any actual education at school, he still managed to do quite well in his quizzes”**

CL: Adpar's learning evidenced; evidence of support from school

LG: Parent acknowledges that school made progress but then undercuts that with remark about lack of actual education. Passive-aggressive behaviour.

**“His brother is in top 5% for his IQ ... he's been assessed to be in the top 10%”**

CL: GE has had, and has accepted, assessments from professionals (her listing of possible diagnoses further shows acceptance of professional input.)

LG: Parent vague

**“I'm that sort of person ... When I'm with my children, we just do things anyway like pumpkin carving, you know.”**

CL: GE shows some self-awareness

LG: Sounds vague and unlikely. Immediately undermined by son. Accepts contradiction. Not concerned about being believed by interviewer.

**“We'll do more formal things at home and I lesson plan as well”**

CL: GE self-awareness/confidence

LG: Contradicts earlier account but sounding more focused and organised.

**“No ... It's just me doing it because I don't want him to not have a job when he comes to work”**

CL: Overwhelmed by situation; is not sharing Adpar's education by choice, but from perceived necessity

LG: Parent taking everything on herself. Looking to the future.

**“I used to teach in schools. I taught IT in Primary School, so. I've got a degree in Childhood and Youth Studies, so I'm from that kind of background.”**

CL: GE self-awareness

LG: Surprising. Parent been underplaying own expertise.

***“If the school were able to give you help, with resources and information, would that help you?”***

**[Laughs] “Probably not, if I'm honest. “**

CL: Lack of confidence in school

LG: Parent resists help but acknowledges irony of that: self-aware.

**“I think I know a lot more about my child, you see ... because I know what works.”**

CL: seems perhaps to be referring solely to what works behaviourally to prevent Adpar from going into meltdown; her responses to questions about learning lack conviction.

LG: When talking about her own input, she increases in confidence and talks over son, ignoring interruptions. She reinforces his negative attitude towards school.

**“Yeah” ... “Okay, yeah” ... “so, you know.”**

CL: Lack of response. Not confident

LG: Parent back to being passive.

*Appendix 5: Questionnaire sorted thematically*

- The child with autism needs more 'down time' than the typical school day gives
- The child may feign illness and/or actually become ill to avoid longer times at school
- Extra time at home allows for closer emotional bonds to develop between the child with autism and parents/family
- Time shared between home and school allows for the development of self-knowledge in the child
- All children with autism present differently, and schools struggle to accommodate all the differences
- School may be able to suggest strategies that can be helpful at/translated to home
- Shared education facilitates communication and continuity between home and school
- Support time at home means the child can do better at school
- Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs
- Shared education allows for sharing of expertise, both home to school and school to home
- Parents often become expert in their children's autism needs and this expertise should be recognised
- Responsibility for a child with autism's special educational needs rests with the parents
- Home-education can be tailored to meet the child's more specific needs
- Mainstream schools do not have the resources to provide the specific therapies that children with autism need
- Learning in school is not functional if it cannot translate for the autistic child to home/the outside world
- Parents of autistic children are in a position to see the 'bigger picture' of their child's development
- Time at home allows for the child to follow his own interests and develop his own coping strategies
- It is hard for parents to provide the additional autism support necessary if the child is in school all day/exhausted when he comes home
- Shorter time at school/more time at home can lead to a happier child – which has a positive effect on the whole family
- Parents may be the only people who love/understand a child with autism; that acceptance may be essential for the child's self esteem
- Parents may have developed strategies that work, but which may be impractical to

translate into school

- Schools are not set up to support an academically able child with autism who has behavioural difficulties which disrupt other pupils' learning
- Parents are frustrated if they feel that school is merely containing their child and that he is not learning
- Schools may see an autistic melt-down as the problem rather than understanding the problems which lead to that melt-down
- Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way
- The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism
- Types of assessment at school may not fairly reflect the understanding of the child with autism (over or under estimating understanding.)
- Children with autism may lack the communication skills to indicate distress/lack of understanding, so parents need to be more fully involved in order to 'translate'
- Parents are not sharing education through choice but because their child with autism is indicating (either verbally or through behaviour) that it is necessary
- Sharing education between home and school can benefit the child with autism

#### Needs of child

- The child with autism needs more 'down time' than the typical school day gives
- The child may feign illness and/or actually become ill to avoid longer times at school
- Time at home allows for the child to follow his own interests and develop his own coping strategies
- Shorter time at school/more time at home can lead to a happier child – which has a positive effect on the whole family
- Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way
- The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism
- Children with autism may lack the communication skills to indicate distress/lack of understanding, so parents need to be more fully involved in order to 'translate'

#### Challenges faced by schools

1. All children with autism present differently, and schools struggle to accommodate all the differences
2. Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs
3. Learning in school is not functional if it cannot translate for the autistic child to home/the outside world
4. Parents may have developed strategies that work, but which may be impractical to translate into school
5. Schools are not set up to support an academically able child with autism who has behavioural difficulties which disrupt other pupils' learning
6. Parents are frustrated if they feel that school is merely containing their child and that he is not learning
7. Schools may see an autistic melt-down as the problem rather than understanding the problems which lead to that melt-down
8. Types of assessment at school may not fairly reflect the understanding of the child with autism (over or under estimating understanding.)

#### **Communication skills/responsibility of parents**

Extra time at home allows for closer emotional bonds to develop between the child with autism and parents/family

Parents often become expert in their children's autism needs and this expertise should be recognised

Responsibility for a child with autism's special educational needs rests with the parents

Home-education can be tailored to meet the child's more specific needs

Parents of autistic children are in a position to see the 'bigger picture' of their child's development

It is hard for parents to provide the additional autism support necessary if the child is in school all day/exhausted when he comes home

Parents may be the only people who love/understand a child with autism; that acceptance may be essential for the child's self esteem

Parents are not sharing education through choice but because their child with autism is indicating (either verbally or through behaviour) that it is necessary



### **Sharing benefits both**

- Time shared between home and school allows for the development of self-knowledge in the child
- School may be able to suggest strategies that can be helpful at/translated to home
- Shared education facilitates communication and continuity between home and school
- Support time at home means the child can do better at school
- Shared education allows for sharing of expertise, both home to school and school to home
- Sharing education between home and school can benefit the child with autism

Thank you for your interest in this research study.

Your initials: \_\_\_\_\_

Please tick as applicable:

I am the parent of a child with autism who shares the child's education between home and school

I am a school professional (role: \_\_\_\_\_) involved in sharing the education of a child with autism between home and school

I am other than the above (please specify): \_\_\_\_\_

\_\_\_\_\_

The following 30 statements are summaries of comments made by some parents who share the education of their child with autism between home and school.

Please indicate in each case whether you agree with the statement, disagree with the statement or are unsure. There is space after each statement for you to comment on it or to clarify your response, if you would like to do so. Please feel free to leave blank any responses you would prefer not to give.

Thank you,

Clare Lawrence

ClareLawrence101@gmail.com

**Supervisors: Dr Luke Beardon** L.Beardon@shu.ac.uk

**Dr Anne Kellock** A.Kellock@shu.ac.uk

- The child with autism needs more 'down time' than the typical school day gives

Agree Disagree Unsure

Comment:

- The child may feign illness and/or actually become ill to avoid longer times at school

Agree Disagree Unsure

Comment:

- Extra time at home allows for closer emotional bonds to develop between the child with autism and parents/family

Agree Disagree Unsure

Comment:

- Time shared between home and school allows for the development of self-knowledge in the child

Agree Disagree Unsure

Comment:

- All children with autism present differently, and schools struggle to accommodate all the differences

Agree Disagree Unsure

Comment:

- School may be able to suggest strategies that can be helpful at/translated to home

Agree Disagree Unsure

Comment:

- Shared education facilitates communication and continuity between home and school

Agree Disagree Unsure

Comment:

- Support time at home means the child can do better at school

Agree Disagree Unsure

Comment:

- Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs

Agree      Disagree      Unsure

Comment:

- Shared education allows for sharing of expertise, both home to school and school to home

Agree      Disagree      Unsure

Comment:

- Parents often become expert in their children's autism needs and this expertise should be recognised

Agree      Disagree      Unsure

Comment:

- Responsibility for a child with autism's special educational needs rests with the parents

Agree      Disagree      Unsure

Comment:

- Home-education can be tailored to meet the child's more specific needs

Agree      Disagree      Unsure

Comment:

- Mainstream schools do not have the resources to provide the specific therapies that children with autism need

Agree      Disagree      Unsure

Comment:

- Learning in school is not functional if it cannot translate for the autistic child to home/the outside world

Agree      Disagree      Unsure

Comment:

- Parents of autistic children are in a position to see the 'bigger picture' of their child's development

Agree      Disagree      Unsure

Comment:

- Time at home allows for the child to follow his own

Agree      Disagree      Unsure

interests and develop his own coping strategies

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • It is hard for parents to provide the additional autism support necessary if the child is in school all day/exhausted when he comes home | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Shorter time at school/more time at home can lead to a happier child – which has a positive effect on the whole family | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Parents may be the only people who love/understand a child with autism; that acceptance may be essential for the child's self esteem | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Parents may have developed strategies that work, but which may be impractical to translate into school | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Schools are not set up to support an academically able child with autism who has behavioural difficulties which disrupt other pupils' learning | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Parents are frustrated if they feel that school is merely containing their child and that he is not learning | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| • Schools may see an autistic melt-down as the problem rather than understanding the problems which lead to that melt-down | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |   |       |          |        |
|---|-------|----------|--------|
| <ul style="list-style-type: none"><li>• Schools may not appreciate the stress/depression/despair of the autistic child if it is not manifested in a typical way</li></ul> | Agree | Disagree | Unsure |
|---|-------|----------|--------|

Comment:

- |   |       |          |        |
|---|-------|----------|--------|
| <ul style="list-style-type: none"><li>• The experience of school is more exhausting for the autistic child so that what is manageable by other children may not be so for the child with autism</li></ul> | Agree | Disagree | Unsure |
|---|-------|----------|--------|

Comment:

- |   |       |          |        |
|---|-------|----------|--------|
| <ul style="list-style-type: none"><li>• Types of assessment at school may not fairly reflect the understanding of the child with autism (over or under estimating understanding.)</li></ul> | Agree | Disagree | Unsure |
|---|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| <ul style="list-style-type: none"><li>• Children with autism may lack the communication skills to indicate distress/lack of understanding, so parents need to be more fully involved in order to 'translate'</li></ul> | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |  |       |          |        |
|--|-------|----------|--------|
| <ul style="list-style-type: none"><li>• Parents are not sharing education through choice but because their child with autism is indicating (either verbally or through behaviour) that it is necessary</li></ul> | Agree | Disagree | Unsure |
|--|-------|----------|--------|

Comment:

- |   |       |          |        |
|---|-------|----------|--------|
| <ul style="list-style-type: none"><li>• Sharing education between home and school can benefit the child with autism</li></ul> | Agree | Disagree | Unsure |
|---|-------|----------|--------|

Comment:

## Sensory

## Language

## Social (including bullying)

## Anxiety/exhaustion

## Academic

## Specialist

## Respectful of autism

## Peer modelling/acceptance

## 'Way in' for parents

## Happier child

All children with autism present differently. What is manageable by other children may not be so for the child with autism, who may find the experience of school exhausting. The autistic child may not show stress in a typical way, and his or her behaviour may be misinterpreted by school staff who may, for example, see an autistic melt-down as the problem rather than understanding the problems which led to that melt-down. Mainstream schools seldom have the specialised knowledge necessary to meet complex autism needs, nor are schools set up to support an academically able child with autism who may still have considerable hidden difficulties, which may or may not present as challenging behaviour.

As children with autism may lack the communication skills to indicate distress or lack of understanding, parents should be fully involved in order to translate for them. Parents frequently become expert in their children's autism needs and this expertise should be recognised and used by schools. Parents are frustrated if they feel that school is merely containing their child and that he or she is not learning, especially when they may have developed strategies that they know work for their child.

However, these strategies may be impractical to translate into school and it can be difficult for parents to find time to provide additional autism support at home if the child is in school all day and comes home exhausted. Schools may not have the resources for the specific therapies that children with autism need and these can be provided at home and the time tailored to meet the individual needs of the child. This may include much-needed 'down time', time for the child to follow his own interests and to develop his own coping strategies and self-knowledge. It may also allow for closer emotional bonds to develop between the child with autism and his parents and family.

The extra time spent at home can enable the child to do better at school, both behaviourally and academically. Types of assessment at school may not fairly reflect the understanding of the child with autism. Time at home allows for the sharing of expertise on the child, both from home to school and from school to home. Learning can be made functional for the child with autism's needs. Above all, shared education can lead to a



happier child, which has a positive effect on the whole family. It is provision which can benefit the child with autism, and should therefore be considered as an option should parents wish to pursue it.



Our Ref AM/SW/KW 2-2014  
23May14

Clare Lawrence  
Development and Society  
c/o Blacktree23@gmail.com

Dear Clare,

**Request for Ethical Approval of Research Project**

Your research project entitled "Can sharing education between home and school benefit the child with autism?" has been submitted for ethical review to the Faculty's rapporteurs and I am pleased to confirm that they have approved your project.

I wish you every success with your research project.

Yours sincerely

  
Professor A Macaskill  
Chair  
Faculty Research Ethics Committee

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